

Overview of the Impact and Best Practice Responses in Favour of Children in a World Affected by HIV and AIDS

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Introduction

During the last decade, the AIDS pandemic has seriously hindered achievement of the child survival and development goals set with such hope at the World Summit for Children in 1990. This is particularly true of the some 40 countries with adult prevalence above 1 per cent; in countries with medium to high prevalence, AIDS has more than wiped out the child mortality gains realized during the 1980s. Moreover, the prospects for the future are not encouraging, as in some 20 countries adult prevalence and the under-five mortality rate (U5MR) are expected to peak only around the middle of the next decade. Low coverage of antiretroviral treatment to treat the virus means that the rate of deaths from AIDS-related illnesses and numbers of children orphaned by the epidemic will continue to rise, even in countries with declining prevalence. At the global level, the well-being of children will depend on the trends under way in large countries such as China and India. While prevalence in these countries is under 1 per cent, there is evidence that the epidemic has now entered an exponential growth phase that will cause a worsening in child well-being over both the short and long term.

This book reviews the community and public policy interventions introduced so far to moderate the impact of the disease on children and families, and discusses the advantages and limitations of such interventions. The main constraint to the measures introduced so far is their nearly exclusive focus on prevention and the health sector. While this approach is understandable in the early phase of the epidemics, its ability to protect child well-being now appears limited. Indeed, even the countries that successfully reduced adult prevalence are now confronted with a rise in the number of paediatric AIDS cases and AIDS deaths among parents and orphans.

In the absence of more decisive policy action, the prospects for child well-being

will remain problematic. A broader policy approach to the response to AIDS is necessary and feasible, though even in the best of all possible worlds some of the negative effects of the disease will continue to be felt over the long term. A number of best practice policy and programme measures could help protect the well-being of children, but the first step is to stop pretending that progress is really being made against HIV and AIDS. It would be better to recognize that so far all too little has been done to confront the disease effectively.

Context and focus

The broad facts about the AIDS epidemic are known to everybody: at the end of 2005 about 40 million people were infected worldwide, and over 20 million people had already died from AIDS since the beginning of the epidemic in 1981. Three million people died in the year 2005 alone. Of the people infected with HIV, 95 per cent live in low- and middle-income countries, primarily sub-Saharan Africa (UNAIDS 2004). While HIV prevalence has started to decline in a limited number of countries, in several others adult prevalence is expected to peak around 2005, while there is a risk that in the years ahead, the contagion could spread rapidly in China, India and Russian Federation, where prevalence is still fairly low but rising at an alarming rate.

Interestingly, while this broad picture is well documented and widely appreciated, the same cannot be said about the impact of HIV on children. While there are excellent statistical compilations and analyses in some problem areas (e.g. orphans) or programmatic responses (awareness campaigns for youth or programmes to combat mother-to-child transmission of HIV), broad-based assessments of the impact of HIV on children are few and far between. Updated information on their impact on the most basic indicators of child well-being – the infant mortality rate (IMR), under-five mortality rate (U5MR) and school enrolment rates – is not readily available. Nor are there accurate data on the number of paediatric AIDS cases.

This study therefore attempts to fill in part of this knowledge gap, and this chapter offers an overview of the impact of HIV on children and desirable policy responses, based on the evidence provided by the case studies and the analyses in the thematic chapters, together with other literature on the subject. First of all, a few preliminary observations:

- For the children of the families affected, the impact of HIV is, without exception, consistently and clearly devastating. But at the macro level, i.e. at the level of national averages for child well-being indicators, the impact only starts to be perceptible when the prevalence exceeds 3–4 per cent. In countries with prevalence around 2–3 per cent (such as Benin, Ghana, Mali and Thailand), the IMR and U5MR continued to decline on trend during the 1990s. In contrast, in about 15 of the 40 countries analysed, the impact of HIV has been very pronounced.

- Even when a country does succeed in controlling HIV prevalence, it might not be equally successful in reducing the numbers of those dying or being orphaned due to AIDS, or in combating child poverty and supporting the care, socialization and emotional development of orphans and abandoned children.
- While deterioration at the macro level may be evident, the sectoral effects are not necessarily uniform or felt at the same time. The first measurable impacts are likely to be on the quality of education, infant and child mortality rates, and perhaps child nutrition (though evidence in this field is limited). Rises in teachers' absenteeism, and declines in contact time and morale, are also rapid. Services for non-HIV-infected patients in public hospitals also frequently deteriorate quickly. However, increases in the numbers of children orphaned by AIDS, or collapse of the education system due to school staff dying of AIDS, or the overall impoverishment of families and children because of reduced economic growth, are likely to be felt much later after the initial onset of the epidemic. This is because such impacts occur as the result of the deaths of a large number of parents, teachers and workers, and HIV-positive adults often live for several years after contracting the virus. And some long-term effects – such as those related to the emotional deprivation and mental health of orphans growing up in difficult social arrangements – are only now starting to be perceived.
- In several low – and high – prevalence countries, much of the impact of HIV on children still lies ahead. This is clearly the case in high-prevalence South Africa – where the rate is expected to peak around the middle of the decade – as well as in China and India. Although the epidemic is still at an early stage, with 5.1 million HIV-positive people, India has the largest number of people living with HIV outside South Africa (UNAIDS 2005). In China, the number of HIV-positive people has risen exponentially since 1993 in parallel with the increase in sexually transmitted infections. At the end of 2001, it was estimated that 660,000 people were infected. By the end of 2003, the total had reached 840,000 and the national adult prevalence was estimated at around 0.1 per cent (UNAIDS 2004). In the absence of timely and decisive interventions, the epidemic could spread rapidly. The experience of countries such as Senegal and Thailand could provide valuable examples of prevention and mitigation.

Social epidemiology of the disease

A good understanding of the social dynamics of HIV is essential for the design of effective policy responses – particularly those that aim at prevention.

i) Bio-medical factors include the prevalence of sexually transmitted infections (STIs), poor health and nutritional status, male circumcision and sexual behaviour. STI levels have a major impact on the risk of contracting HIV, but STIs often go

untreated because they tend to be asymptomatic. Data from Kenya show that people with STIs were found to be up to four times more likely to contract HIV than those without. Male circumcision also reduces the risk of contagion (K'Oyugi and Muita 2002).

- In China the **over-use of curative injections** (and tattooing) is another source of infection. It is estimated that children under five are given an average of six injections per year (chapter 6), a fact that certainly contributes to the spread of hepatitis B and to the transmission of HIV. About half the curative injections in China are unsafe because of improper sterilization practices.
- In parts of China, the **sale of blood** is a common survival strategy adopted by the poor. Many sell their blood several times a month for a fee of \$5. Blood from people with the same type is pooled and centrifuged to separate the plasma, which is then sold. The remainder of the pooled blood is re-injected into the farmers. As a result, some 1 million people were infected in Henan province alone. In extreme cases, as in blood donor villages in Hebei and Hubei, up to 75 per cent of the people selling their blood tested positive. An October 1998 law banned the sale of blood, but chronic blood shortages, money incentives for the poor and lack of information about HIV make it difficult to eliminate this phenomenon.

ii) Social risk factors. An important factor is **high mobility**, caused by temporary migration, forced displacement (e.g. for refugees and internally displaced persons (IDPs)), or the demands of professions involving protracted absences from the family, as is the case with truckers, fishermen, soldiers, contract labourers working on construction projects, sales representatives, tradesmen and seasonal workers on commercial farms. Truckers seem to be particularly at risk. In Zimbabwe in 1996, 30 per cent of the staff of a major transport company was HIV-positive. A study of a rural community in KwaZulu-Natal showed that people who had recently changed place of residence were three times more likely to be HIV-positive than those who had not. In chapter 5, Janjaroen and Khamman show that migration from neighbouring poor areas of Cambodia and Myanmar are a possible factor in the recent upsurge of HIV prevalence in Thailand. Even in low-prevalence Senegal (chapter 3), HIV prevalence of 23 per cent was reported among the adults of villages where there had been significant emigration.

Domestic **migration** leads to rapid urbanization, which is often associated with the spread of STIs and HIV because of the loosening of social norms regulating premarital sex, lack of sanctions against promiscuity and numerous opportunities to make contacts within a setting of anonymity and low social control. In China, the spread of HIV has probably been facilitated by the massive internal migrations that have involved a 'floating population' of over 100 million people. Local surveys from Shanxi show that, of the people who had been found to be positive, two thirds were migrant workers (chapter 6).

- **Location:** HIV prevalence is generally higher in urban than rural areas. Yet, there is evidence that the urban–rural ratio may be reversed over time as prevalence may fall in urban areas because of raised awareness, while the rate in rural areas may catch up. This can happen, for instance, if rural areas provide seasonal manpower to urban areas.
- The incidence of HIV also varies with **social status**. Jobs that give social status and power – as is the case with army personnel (Cambodia, Thailand and Yunnan Province, China) and wealthy managers – exhibit higher rates of infection than the average for males (but not for women). Teachers and health workers enjoy social status and are likely to live away from their families. This exposes them to a greater risk of engaging in sex with multiple partners.
- **Income level and distribution**, poverty, unemployment and marginalization raise the risk of contagion in urban areas. Poverty and uncertainty about the future can lead to short-term survival strategies with risky behaviour. Unemployment and social exclusion are key factors in drug addiction and the risk of infection through intravenous drug use. Income inequality also tends to affect the cohesion of local communities and to reduce their cooperative behaviour.
- **The empowerment of women**, in terms of employment, income and social roles, tends to reduce the risk of contagion. Reducing discrimination against women in these areas increases their independence and ability to negotiate sexual contacts on their own terms. This particularly benefits young girls, who because of existing social norms often get infected at a much younger age than men. A study from South Africa shows that an increase in the income and status of a man tends to increase his risk of infection while the opposite is true for women. A redistribution of income among genders and social classes would therefore reduce HIV incidence. Cross-sectional evidence from Kenya (K'Oyugi and Muita 2002) seems to confirm this finding.
- **Education level.** In the first stage of the HIV pandemic, educated men were particularly hit by HIV as their status allowed them to engage in multiple sexual relationships, effectively exposing them to greater risks of contagion. With the spread of information on prevention, incidence rates in this group have fallen, and most of the burden of the epidemic has shifted to people with lower levels of education and less ability to absorb messages about prevention.

iii) Cultural norms. Cultural and religious beliefs and practices, such as attitudes towards early, premarital and extramarital sex, marriage, prostitution, sexual education, condom use, polygamy and wife-sharing, blood brotherhood, widow inheritance and so on, affect the risk of HIV infection. Beliefs about specific sexual practices, such as the supposed curative effects of intercourse with young virgins and the obligation of cleansing sexual practices with widows of deceased

family members, are localized examples of norms contributing to the spread of the disease. K'Oyugi and Muita's data from Kenya show that women's risk of becoming HIV-positive varies with their marital status. It is significantly higher among those in polygamous, rather than monogamous, marriages. And it is three times as high among widows (K'Oyugi and Muita 2002).

iv) Political events. Areas such as the Great Lakes Region of Africa that have witnessed a large rise in the number of refugees, IDPs and soldiers concentrated in temporary camps are also particularly exposed to the risk of infection.

Changes in the well-being of children in countries affected by HIV

Three categories of children have been directly affected by the epidemic: children who have been abandoned or orphaned by AIDS, those who are HIV-positive themselves and those living in families with HIV-positive parents. But many other children have also been affected indirectly. Among them are children suffering from malaria or other diseases, who find it more difficult to access health-care systems overloaded by the HIV emergency, and children living in areas where the economy has contracted because of HIV, who therefore find it more difficult than before to extricate themselves from poverty.

Changes in infant and child mortality during the 1990s

Overall impact: In chapter 10, Cornia, Patel and Zagonari show that in the 1990s U5MR mounted rapidly in eight countries from Eastern and Southern Africa with high adult HIV prevalence and pre-AIDS coverage of child health services. Child mortality also increased in 'failed states' and – more moderately – in Burundi, Cameroon, Côte d'Ivoire and Rwanda. All these countries experienced a reversal of the trend towards lower child mortality. The average extent of the reversal in the first group was 20–30 per cent, but in Botswana, where AIDS more than erased all the reductions in child mortality achieved during the 1980s, it reached 80 per cent. A sample of 40 countries shows that a 1 per cent increase in adult HIV prevalence raises U5MR by 1.9 points per thousand. AIDS may also have been responsible for the slower than trend decline in U5MR in a few countries such as Benin, Burkina Faso, the Dominican Republic and Ghana, which had a low to moderate HIV prevalence and a steady expansion of health services for children. In contrast, in some 10 countries, the moderate surge in AIDS-related child mortality was more than offset by a reduction in the rate, thanks to an expansion of immunization coverage, maternity care and other health interventions. Because of their initial paucity of services, these countries benefited from the 'basic health services dividend', despite AIDS.

In several countries, the unfavourable trend in U5MR will continue in the years

ahead. In South Africa it has been estimated that the rate will rise from 95 to 110 per thousand between 2001 and 2006. In KwaZulu-Natal, the most affected province, it is expected to exceed 140 per thousand in 2006, more than double the rate for 1992 (chapter 4).

The observed rise in U5MR can, in principle, be attributed to three sets of factors. First, infants born to an HIV-positive mother have a 25–45 per cent probability of being infected by the virus, contracting AIDS and dying in one to three years after birth. Second, child mortality due to infectious, airborne and waterborne diseases may rise if the demand for palliative care and the care of opportunistic infections crowds out expenditure on immunization and other health programmes for children. Evidence from a number of studies suggests that the 1990s witnessed a resurgence in the number of cases of malaria, diarrhoea and malnutrition. While available data do not show a conclusive relationship between the HIV epidemics and these changes, the diminution of primary health care (PHC) and increased pressure on secondary and tertiary care generated by HIV might be a contributing factor.

In addition, the surveys undertaken during the course of the research for this book show that children in families in which the head of the household died of HIV-related illnesses had a distinctly higher risk of death than children in families where there was no death or where the household head died from some other cause. This evidence is clearly borne out by surveys in Sangli, Maharashtra, India (Verma et al. 2002), Côte d'Ivoire (Pégatiéan and Blibolo 2002) and the Ugunja Division of the Siaya District in Kenya (K'Oyugi and Muita 2002). In Kenya, the child mortality rate in the families affected by HIV over the 18 months preceding the date of the interviews (May 2001) was 16.7 per cent, compared with about 5 per cent in the two control groups. The same surveys showed that one possible explanation was the reduced access to health care in HIV-affected families (table 1).

Table 1. Percentage of children unable to attend a clinic during the survey period by type of family, 2001

	AIDS death	Non-AIDS death	No death
Sangli, Maharashtra (India)	23.4	17.7	8.7
Ugunja, Kenya	43.0	42.3	36.9
Côte d'Ivoire	48.7	26.8	29.5

Source: Author's compilation of data provided from case studies cited above.

Third, mortality among children may also rise because of the HIV-induced impoverishment of the family in which the child lives. As discussed in chapter 7, the average income of families whose head had died of an HIV-related illness during the prior 18 months dropped by up to 50 per cent.

Increased mortality due to paediatric AIDS: In 1999 alone, 570,000 infants became infected with HIV worldwide, bringing their total number to 1.2 million. At the end of 2005 there were an estimated 2.3 million children under 15 living with HIV (UNAIDS 2005). By end-2003, there were 1.9 million children in sub-Saharan Africa alone (UNAIDS 2004). Mother-to-child transmission accounts for over 90 per cent of the paediatric AIDS cases; the remaining 10 per cent contract the virus from contaminated blood products or non-sterile skin-piercing instruments. As noted by Phiri and Webb in chapter 11, a study in Uganda found that roughly a third of HIV-positive children died in their first year, half died by 21 months and three quarters after five years. Similarly in Malawi, some 90 per cent of HIV-infected children do not survive beyond their third birthday. Several studies have shown that the mean age of death of children born HIV-positive is 2.2 years.

Lack of data on the incidence of paediatric AIDS means that, when assessing the reasons for increases in U5MR, it is not possible to distinguish between the impact of HIV infection in children and that of impoverishment and reduced access to health care. However, anecdotal evidence shows that most (but not all) of the observed increase in U5MR can be attributed to the rise in HIV prevalence among pregnant women. In South Africa, already in 1997, half the admissions to paediatric wards were due to HIV. In areas of the country with very high rates of infection, as many as three quarters of the beds in children's wards were occupied by children with HIV-related illnesses. This finding provides a strong rationale for stepping up programmes to provide universal coverage of nevirapine to newborns. Indeed, while immunization, oral rehydration therapy (ORT), delivery care, breastfeeding and child nutrition appear to have a perceptible effect on child mortality, especially when they are directed to educated mothers, their impact is more than offset in countries with high rates of adult HIV prevalence. As chapter 10 shows, a 10 per cent rise in adult HIV prevalence more than erases a similar expansion of diphtheria, pertussis and tetanus (DPT) immunization, fresh water supply, ORT, maternity care and breastfeeding during the first three months of life.

Changes in child nutrition: HIV affects child nutrition in at least three ways. First of all, most young children born HIV-positive begin to manifest symptoms of infection during their first year of life. Many therefore suffer from stunting and wasting because of frequent attacks of diarrhoea and other opportunistic infections. In Côte d'Ivoire, a strong association was found between HIV prevalence and malnutrition among children (Pégatiéan and Blibolo 2002). Second, the large decline in income suffered by families with an AIDS-related death (chapters 7 and 8) imposes considerable cuts in food expenditure (table 2) that may affect child nutrition. In the case study on Senegal (chapter 3), Nyang and Van Ufford show that the practice of reducing food diversity has increased among HIV-affected families but not among the others. While cuts in food expenditure may be tolerable for the children of middle-income families, their impact among the poor is much more problematic and may lead to increased child malnutrition.

Table 2. Percentage of families that have reduced their basic food budget

	AIDS death	Non-AIDS death	No death
Ugunja, Kenya	30.6	29.4	26.7
Côte d'Ivoire	27.0	23.8	11.3

Sources: Data from Cornia 2002 and Pégatiéan and Blibolo 2002.

Third, malnutrition may also rise among children not directly affected. In chapter 11, Phiri and Webb show that nutrition is reduced for children in families that take in orphans, as the scarce family resources are redistributed among a growing number of children.

Changes in educational achievement

Trends in enrolment and dropout rates: Since the early 1980s, and throughout the 1990s, the gross primary enrolment rate stagnated or declined in 22 of the 41 sub-Saharan African countries with adequate data. Some of the greatest declines were observed in HIV-affected countries, such as Kenya, South Africa and United Republic of Tanzania, though some HIV-affected countries did not suffer any decline or – as in the case of Uganda – recorded steady improvements in enrolment rates. Desmond and Gow illustrate the rapid decline in primary enrolment rates (from 130 per cent to 86 per cent) recorded in South Africa as a whole from 1995 to 1997, and the equally large drop over the following four years in KwaZulu-Natal. Similar aggregate trends were seen in Kenya, but not in Thailand, Uganda or low-prevalence Yunnan, China.

At the aggregate level, the relationship between HIV and educational achievements is far from simple, as it is also influenced by economic recessions, conflicts and shifts in educational policy. At the individual level, the relationship between HIV and enrolment rates is much clearer. The well-known World Bank study on Kagera (United Republic of Tanzania) shows that the enrolment rate of 7-10-year-old children in non-AIDS-affected families was 44 per cent, while among affected families it was 28 per cent. Similar results were found in Ugunja, Kenya (table 3) that point to higher dropout rates among children orphaned by AIDS. Analysis of the Kenyan data shows, however, that, as incomes rose, the risk of such children being withdrawn from school declined.

Table 3. Percentage of children 7–15 withdrawn from school in different types of families, 2001

	AIDS death	Non-AIDS death	No death
Ugunja, Kenya	23.9	19.1	14.8
Côte d'Ivoire	27.7	18.5	16.0
Rural South Africa*	14.0	6.0

Sources: Data from chapter 4, Pégatiéan and Blibolo 2002 and Cornia 2002.

Notes: * Refers to children 14–18 years old not attending school. No significant difference was found for children in primary school and urban areas.

The data derived from the Senegalese survey (chapter 3) suggest a less pronounced, but still worrying, tendency as 6 per cent of the adults declared that, as a result of HIV, at least one of their children was dismissed from school. In addition, children with HIV may have faced problems of integration and, although no systematic discrimination was observed in schools, they were more likely to attend Koranic schools.

Finally, the data from Uganda suggest that public policy can help expand enrolment rates, even in the midst of a severe AIDS epidemic, if there is a deliberate strategy to focus on expanding educational opportunities. In an effort to achieve Universal Primary Education, the Ugandan Government substantially raised the number of new schools and primary and secondary teachers and abolished school fees. The message seems to be clear: while HIV affects both the demand for and supply of education, appropriately directed educational policy can minimize its impact and sustain progress in several aspects of education.

HIV also affects the quality of educational services. Teachers are lost through death, attrition and transfers. In Malawi, Namibia and Zambia, HIV infection rates of up to 40 per cent have been reported among teachers. Even if they could be replaced, the quality of education would be affected, as new teachers entering the educational system would lack the experience of the older ones lost to AIDS. HIV-related illness also means that educators become less productive. Ill teachers are affected by low morale, frequent absences, reduced contact time with students and difficulties in concentrating in the face of illness, death, mourning and dislocation. In Côte d'Ivoire (Pégatiénan and Blibolo 2002), the average sick leave of HIV-positive teachers was 6.2 months, as against 10 days for non-infected teachers. And the loss of school administrators means that the overall management of the educational system may deteriorate.

Children from affected families also face a more difficult situation in school. In Senegal, children from HIV-affected families who remained in school frequently had to miss class (due to their involvement in domestic duties), obtained poor results, and faced difficulties in buying school stationery. As Coombe notes in chapter 9, all this adds up to a school environment characterized by distress, anxiety, confusion and lower teaching efficiency. Without a strong policy response, the quality of education is bound to suffer in such an environment.

A rising number of children orphaned by AIDS

UNAIDS estimates that at the end of 2003 there were 15 million children 0–17 years old worldwide who had been orphaned by AIDS. This figure was up 3.5 million from 2001. The crisis is worst in sub-Saharan Africa, where in 2003 there were 12 million children who had lost one or both parents to AIDS. The total is expected

to reach 18 million by 2010 (UNAIDS 2004). However, as argued by Phiri and Webb in chapter 11, this figure grossly underestimates the true scale of the problem as it does not include the 'social' orphans. In their view, more realistic figures would be two to three times higher. When expressed in percentage terms, the rate appears even more frightening. In a low- and middle-income country with no AIDS, an average 2 per cent of children (0–18 years) are orphaned. But in 2000, in the 34 countries most affected by HIV, the average was 10.9 per cent; it was as high as 27.4 per cent in Zambia and 25.7 per cent in the Central African Republic. By 2010 it is expected to reach an average of 12.6 per cent, while in Botswana, Namibia and South Africa it will range between 30 per cent and 36 per cent, a tragedy never observed in known history, not even during the Black Death that hit medieval Europe.

In China, the problem is likely to remain much more limited, at least over the next 10 years, partly because of the lower birth rate. In Yunnan Province, the number of children orphaned by AIDS is expected to rise to 21,000 by 2010. Although less alarming than in other countries, the rise is very sharp and will pose considerable problems because of the lack of institutions and policies in this area.

It is important to stress that the problem of children orphaned by AIDS is a long wave one that will last well after the peak of the HIV epidemic has passed. Indeed, the 'orphan epidemic' is still in its infancy and is expected to grow to devastating proportions over the next 10 years. Thus, while Thailand started reducing its HIV adult prevalence in 1995, the number of orphaned children rose from some 20,000 in 1995 to 126,000 in 2002 and is expected to reach 160,000 by end-2005. With rates of HIV prevalence still on the rise in the majority of countries, there will be children orphaned by AIDS for at least two more generations.

Orphaned children face a long series of material deprivations. Growing up in families with infected, weakened and dying parents, they experience a fall in their food intake, greater likelihood of dropping out of school and starting to work, diminished access to health care and higher risk of mortality. But even if they were assured a minimum of material resources, the children would face an uncertain future and a considerable affection and socialization deficit. In the best of circumstances, the death of the parents means that they face emotional deprivation and psychosocial stress and possibly suffer from mental ill health. The emotional, psychological and mental damage suffered by these children is only slowly being recognized and the related emotional, socialization and mental health problems are still to be addressed.

One of the most significant impacts of HIV on orphans is not only the collapse of their families but also the disintegration of their traditional social arrangements, support structures and social relations. Orphans face mounting stigmatization in school. In Malawi, as a result of stigma and social exclusion, children tend to form

their own informal peer groups. As shown in table 4, even in a low-prevalence location such as the Sangli district of Maharashtra, they are strongly discriminated against by their peers (Verma et al. 2002). Orphans also have to assume a prematurely adult role.

Table 4. Percentage of children discriminated against in school or at play by type of family, 2001

	AIDS death	Non-AIDS death	No death
Sangli, Maharashtra, India	20.1	2.8	3.1
Ugunja, Kenya	6.8	1.8	1.8

Sources: Data from K'Oyugi and Muita 2002 and Verma et al. 2002.

Finally, there is hardly any indication of the long-term effect on their future adult behaviour (as parents, workers, citizens) of the lack of parental affection, guidance and supervision suffered by a huge number of children now growing up in material and emotional poverty.

Another indirect effect of HIV is the number of children who have been abandoned by their impoverished parents and could be termed 'social' orphans. With mounting poverty, distress and social fragmentation, many parents deliberately abandon their children, as they no longer feel able to care for them. HIV-positive mothers, in particular, are afraid of poverty and fear stigmatization. As shown in chapter 5, in Thailand, the probability of being abandoned by an HIV-positive mother is five times that of non-infected mothers. And as noted by Desmond and Gow in chapter 4, over the last three years there was a 67 per cent increase in the number of children abandoned in hospital wards. This trend is corroborated by the sharp increase in the number of street children going to shelters in the last few years. In Swaziland, the number of 'social' orphans now exceeds that of 'natural' orphans (personal communication by officials of Swaziland, Lusaka Seminar on AIDS Orphans 2001).

Economic decline and child poverty

The literature reviewed in chapter 7 by Cornia and Zagonari suggests that the economic impact of HIV depends on the period, prevalence and type of country considered, but that in low-income countries with medium to high prevalence, the epidemic causes a decline of 0.5–1.0 per cent in the annual GDP growth rate. Table 1 of chapter 7 also suggests that families that lost the head of household due to AIDS subsequently experienced a 30–40 per cent decline in household income. In South Africa, where affected households are generally larger than non-affected ones, the decline in adult equivalent income is often 40–50 per cent more than non-affected households. While there is evidence that affected families manage to

reduce the income gap in the two years after the head of household's death, the impoverishment effect lasts several years.

The decline in GDP growth is therefore likely to throw an increasing number of children into poverty, which means governments need to step up welfare payments to poor children, women and the elderly. Chapter 4 estimates that in South Africa, 12 million of the country's 17 million children are classified as living in poverty – a large proportion of them in families with one or two HIV-positive parents. Symptoms of growing poverty also emerge from other sources. In Senegal, the percentage of HIV-affected families whose electricity was cut off for non-payment of bills increased from 4.5 per cent to 12.6 per cent between 1996 and 2000. The number of children living or working on the street also increased everywhere, as has the number of working children in affected families, though the data from surveys undertaken for this book suggest that children are working more within the family than outside.

HIV impact on the supply of social services

One of the many impacts of HIV has been on the public infrastructure that provides basic social services. While these services cover the entire population, in a low- and middle-income country context they are especially central to the well-being of children. Most commentators stress that the impact of HIV in this area has been negative, though two of the case studies included in this compilation also stress positive effects in the health sector. Thus, the health educators who prevent and treat HIV also work on non-HIV-related diseases. Likewise, the desire to prevent the vertical transmission of HIV has led to improvements in obstetric services. And the new procedures introduced for sterilization and the screening of blood have improved the reliability of these services.

Health care

In chapter 10, Cornia, Patel and Zagonari found that HIV crowded out the health resources assigned to the care of traditional sicknesses and directed most of the additional demand for care to the secondary and tertiary levels. This has caused congestion at the upper levels while weakening primary health care, particularly programmes targeted at children. As argued by Basaza and Kaija in chapter 2, there is anecdotal evidence that in Uganda the provision of drugs for treatment of opportunistic infections and STIs produced a considerable increase in attendance at peripheral health facilities.

In Senegal, there is evidence that HIV-affected families had three times more consultations with the formal health care system than non-affected people, and that their average consultation cost was 2.2 times more than that of non-affected families

(chapter 3). In addition, affected families paid two to seven times more than other patients to consult *marabouts*.

While public expenditure on HIV is difficult to measure as it absorbs a proportion of the regular health budget, in most countries (Brazil is an exception) budget allocations to HIV remained modest both in absolute terms, as a share of public health expenditure (table 5) and as a percentage of GDP. This runs counter to the generally held view that HIV causes massive drainage of public resources. In Thailand, the 1992–2001 AIDS budget oscillated between \$30 million and \$60 million, a relatively low 0.02 per cent to 0.04 per cent of the national GDP and only 2–3 per cent of the public health budget.

Table 5. Percentage share of direct expenditure on AIDS in the total health budget 1993–2001

	1993	1994	1995	1996	1997	1998	1999	2000	2001
Côte d'Ivoire	0.15	0.33	0.90	1.25	1.30	0.43	0.51	...	2.80
Thailand	3.21	2.70	2.98	3.44	2.82	2.32	2.30	2.24	2.24
Kenya	1.20	1.30

There are also suggestions that HIV has eroded the delivery capacity of the whole health sector, due to mounting infection rates and deaths among medical staff, falling expenditure on fixed investment and maintenance, and a massive increase in the demand for health services. However, the case study on Kenya (K'Oyugi and Muita 2002) suggests that the higher staff mortality did not reduce the ability of the sector to provide health services, because between 1990 and 2000 the number of doctors and nurses tripled at all levels of care due to the hiring of new staff. The recruitment of new health staff was, however, apparently not due to the desire to combat AIDS, but rather due to a policy of improving geographical access and overall service quality. This was also the case in Côte d'Ivoire (Pégatiénan and Blibolo 2002). Verma et al. (2002) argue that in the Sangli district of India, the stakeholders identified the main problems of the health sector as weakness of the rural infrastructure for preventing, diagnosing and treating AIDS, poor staff training and discrimination against HIV patients.

In China, the problem of public care for HIV has been compounded by the dismantling of the commune-based health care system and the de facto privatization of health services. With the changes in health financing introduced since 1978, most of the rural population and about half those living in urban areas have no health insurance. Out-of-pocket payments have risen sharply and increases in user fees correlate with decreased service utilization. Because of the excessive cost of health services, antenatal care has also declined and so has hospitalization. Meanwhile, unofficial health providers tend to over-prescribe, especially injections, a trend that raises the risk of

infection (chapter 6). This approach to health-care financing is likely to hamper the adoption of appropriate screening and therapeutic approaches for HIV and AIDS.

Education

The impact of the epidemic on the educational sector has been severe, but collapse seems to have been avoided. In most of sub-Saharan Africa (but not in Asia), educators are at high risk of infection because of their relative affluence, mobility and status in the community. As noted, their HIV-positive status affected the quality of education by increasing the frequency and length of the absences from school due to illness and leave for funerals, and because of the psychological impact of the illness on morale and teaching quality.

But the impact of HIV-related deaths on the stock of teachers has been slow to emerge, because of the time lag between infection and death and in some cases the rise in the numbers of new teachers hired. In Côte d'Ivoire, in 1996–1997, out of 218 known deaths of primary school teachers, 140 were due to AIDS, tripling the normal death rate among teachers. But, the impact on the system remained bearable. However, as suggested in chapter 9 by Coombe, World Bank projections for East African countries foresee an annual AIDS-induced loss of 1–2 per cent in the total number of teachers – possibly creating a shortage towards the end of the decade. Similar projections are presented in chapter 4 on South Africa.

But public policy can reverse this emerging gap drastically. In Uganda, deaths among primary school teachers rose from some 650 to 950 between 1995 and 1998 (with half of the increase due to AIDS), yet the total number of teachers in primary education increased from 74,000 to 101,000 and in secondary education from 13,000 to 16,000. This expansion was due to the government's commitment to achievement of the goal of Universal Primary Education.

HIV has, however, confronted the education sector with new challenges. Children orphaned because of the epidemic constitute an entire generation of educationally disenfranchised young people whom the educational system has often not been able to integrate. In many cases orphans drop out of school or are even refused admittance. Some communities believe that children are bound to have HIV if their parents are seropositive, and so try to stop them attending school.

Although evidence is scanty, it is likely that the managerial and policy development capacity of the educational sector has been eroded, so practical strategies to deal with HIV should be put in place. Yet in chapter 9 Coombe argues that little attention seems to have been paid to this requirement. She also argues that there is insufficient research on the costs and implications of the changes needed in teachers' training colleges to adjust the pre- and in-service models and the curricula to the new situation.

Social welfare

Ministries of welfare are traditionally little developed in low-income countries. And though HIV requires an increased supply of social workers, transfer payments and other schemes to support communities, not much has been done to respond to this challenge. The situation obviously varies. In South Africa, the Welfare Ministry has expanded its services and benefits to respond to impoverishment and other problems caused by HIV (chapter 4). But in Côte d'Ivoire, the relevant ministry is very small and its personnel (about 700 social assistants) remains largely under-utilized, although the demand for its services is rising fast (Pégatiéan and Blibolo 2002). The stakeholders felt that the main welfare problem was the rise in the number of orphans and poor. In Sangli district in India, those concerned prioritized food assistance for families with HIV-positive parents as well as the provision of a minimum pension of \$3–\$4 a month for the elderly members in infected families who were about to lose their source of social support.

Community and public policy responses to the problems of children in a world with HIV and AIDS

Prevention of HIV infection

So far, the main response to the HIV epidemic has been preventive programmes, consisting of information and education campaigns (IEC), condom distribution, STI control, blood screening and voluntary counselling and testing. The impact of these programmes is still being evaluated, as some generate inconsistent results. In South Africa, despite a large number of HIV-awareness programmes and information campaigns, a considerable proportion of the population is still ignorant of the basic facts about HIV and AIDS, mainly because of illiteracy, geographical isolation or misinformation. Verma et al. (2002) show that in Sangli district in India, despite many awareness rallies, street plays and poster displays, large segments of the population, particularly those in rural areas, are still unaware of the basic facts about HIV. In Kenya (K'Oyugi and Muita 2002), despite success in making information and services available to some 90 per cent of the population, HIV prevalence remains high because awareness has not led to behavioural change. This is also the case in Botswana, where antenatal survey data and various knowledge, attitude, behaviour and practice (KABP) surveys show that despite high levels of HIV and AIDS knowledge, there has been no change in sexual behaviour.

These findings for Botswana and Kenya confirm the well-known discrepancy between HIV awareness and behavioural change. Yet, behavioural change was observed in Thailand following the launch in 1989 of the '100 per cent condom use programme' for males going to sex workers. In Uganda, however, the relationship between IEC campaigns, behavioural change and the decline in the infection rate

is harder to prove. Indeed, it is difficult to assess the impact of information on changes in risky behaviour.

One of the issues underscored in the studies on South Africa and Uganda is that prevention efforts suffered from several problems. The information campaigns were generally limited to the major urban centres, were of sporadic nature, rarely targeted young people and ignored the educational sector – despite the fact that schools are a major source of infection and could be used as centres for dissemination of information.

Another problem concerns the availability of condoms. Pégatiéan and Blibolo (2002) argue that in Côte d'Ivoire the supply of condoms in 2000 ensured – on average – the availability of only four condoms per year to every sexually active male. Only in some high-risk groups has condom use increased (92 per cent among the customers of sex workers in Abidjan). But, as well illustrated by the China HIV/AIDS Socio-Economic Impact Study Team (chapter 6), surveys show that condom use remains very low throughout China, that condoms are seen as more useful for birth control purposes than for avoiding HIV transmission and are taboo in some areas. Even in the sex industry, condom use is only around 30–40 per cent, and much lower rates of condom use are observed in casual encounters.

Voluntary testing has also generated mixed results. In many countries there are no studies about the acceptability and practicability of testing among the general population. In the absence of any chance of antiretroviral therapy (ART), there is reluctance on the part of both patients and doctors to promote HIV tests, as it is feared that an HIV-positive result might be too great a shock for some people who could become emotionally unstable, get depressed and, in extreme cases, commit suicide. As indicated in chapter 5, in 1966 in Thailand, males with HIV had a 60 per cent higher chance of committing suicide than non-affected people.

Measures against the stigmatization of HIV-positive children

Another major impact is the systematic marginalization of people affected by HIV. Discrimination takes place in every aspect of life – the workplace, schools (see above), clinics, community centres, businesses and play areas. Discrimination against HIV-positive children deprives them of many of their rights, including the right to inherit their dying parents' possessions. Stigma clearly works against prevention. In Phuket, Thailand, fear of stigma and isolation constrains people from disclosing their status, a fact that may not help reduce the spread of the disease. In Yunnan and the rest of China, stigma is much stronger in urban areas – and some hospitals in Beijing even refuse to admit patients with HIV infection. As elsewhere, the impact of this attitude is that people living with HIV do not disclose their status and so make the work of prevention much more difficult.

Despite the gravity of the problem, this is an area in which public policy and community responses have done little and achieved even less. In 1991, awareness-raising campaigns were introduced in Thailand to try and reduce stigma against HIV-positive people, who had until then been represented in the media as a source of danger. Despite all these efforts, the situation has not significantly changed, although levels of acceptance may have improved in some areas. Clearly much more needs to be done. Interviews with stakeholders carried out in connection with research for this book identified stigma as one of the main new problems brought about by the epidemic.

Prevention of mother-to-child transmission of HIV

Despite their enormous potential for saving the lives of children, programmes to prevent mother-to-child transmission (PMTCT) of HIV are not widespread. Only a very few countries, such as Thailand, have gone beyond the pilot project phase and extended such programmes to a significant proportion of the eligible mothers and children. As shown by Janjaroen and Khamman in chapter 5, in Thailand the Ministry of Public Health began in 1993 to provide milk substitutes to children born to HIV-positive mothers, and then started to distribute AZT (azidothymidine) free to pregnant women in two of the country's 12 regions. By 2000, the programme was extended to about half the country; 75 per cent of the women going for antenatal care agreed to be tested and 64 per cent of those who were positive were given short-course AZT. In addition, since 2002, the government has started to provide combination therapy to 500 mothers with HIV, 5 per cent of those included in the PMTCT programme. In cooperation with UNAIDS and UNICEF, the Government of Uganda has launched a similar programme. By end-2001, about half of the 54,000 women attending antenatal clinics had been tested, 3,613 were found to be positive and 1,620 were given nevirapine (chapter 2, table 10).

In South Africa, planning for implementation of nationwide PMTCT activities was at an advanced stage in 2002, but as of end-2004 the programme had not yet received government funding.

Access to antiretrovirals for adults

With appropriate antiretroviral therapy, AIDS becomes a chronic but no longer lethal disease, enabling patients to lead fairly normal lives. If HIV-positive parents live longer, there are likely to be fewer children who are orphaned and emotionally deprived. However, with the exception of middle-income countries such as Argentina, Brazil and Mexico, and countries such as Thailand, only a negligible proportion of the global HIV-positive population has access to ARV therapy.

In 2003, WHO and UNAIDS announced a '3 by 5' target – to reach 3 million people living with HIV in low- and middle-income countries with ARV therapy by

the end of 2005. By June 2005, ARV therapy coverage had more than doubled, from 400,000 to approximately 1 million. That meant that in 14 affected countries, drugs were provided to at least half of those who needed them, while in Latin America and the Caribbean, the proportion of treated patients was up to two thirds. Nevertheless, the target of treating 3 million people was unlikely to be reached by the end of the year.

The scaling up of ARV treatment has been achieved as a result of a broad range of local, national, regional and international efforts, together with support from the Global Fund to Fight AIDS, Tuberculosis and Malaria, the World Bank, non-governmental organizations (NGOs) and the private sector (UNAIDS and WHO 2005).

Care for children orphaned by AIDS and social assistance for the poor

While there has been a great deal of experimentation on optimum ways of caring for children orphaned by AIDS at the local and community-based organization level, public policy has generally lagged behind. The official position has been to focus on community- and NGO-based care. Indeed, in situations of temporary crises, communities have shown themselves able to provide assistance by relying on informal mechanisms. Such responses work well when only a few families are affected, but are unable to cope when the numbers of HIV-related deaths and orphaned children rise significantly. In addition, as shown by Niang and Van Ufford in chapter 3, while the families affected by HIV did benefit from the assistance of neighbours, relatives and friends immediately after revealing their HIV infection, such assistance declined substantially over time, thus suggesting that informal networks can help with short-term crises but not with permanent ones.

As argued by Barnett and Whiteside in chapter 8, public statements about the desirability of relying on communities for the care of orphans and poor children (a position frequently adopted by senior international civil servants and national governments in Africa and Asia) sound like an excuse for protracted inaction and inability to think through the broad-ranging implications of HIV and AIDS. Indeed, in most cases there is no comprehensive policy on how to tackle the problems of orphans and child poverty.

Some countries have adopted a more proactive stance. South Africa's response emphasizes reliance on communities, but also recognizes the need to provide them with financial support. As illustrated by Desmond and Gow in chapter 4, this objective was achieved by the establishment and rapid expansion of a means-tested 'child support grant' (Rand 170 per month) for poor children, an 'orphan foster grant' (Rand 530 per month) and a means-tested 'care dependency grant' for children with severe mental and physical problems (HIV-positive children are not included in this category). The first programme expanded rapidly (from 202,000 children in March

2001 to 3.4 million in July 2003). In March 2001, the orphan foster grant covered around 52,000 children, only 20 per cent of the estimated 250,000 orphans.

In Thailand, the Ministry of Welfare provides free breastmilk substitutes for children of HIV-positive mothers and free school lunches for eligible primary school students. The government also provides cash transfers to the elderly, who often raise grandchildren, and suffer from emotional stress and loss of support due to the HIV infection of their adult children. After the 1997 financial crisis, the value of the transfer rose from Baht 200 to Baht 300 per month and coverage increased from 300,000 to 400,000 recipients. In addition to the government, there is a network of over 500 privately run organizations that provide various types of welfare assistance, and more than 100 registered NGOs concentrating on development programmes for Thai children and youth. All concerned are trying to solve the inevitable problems of coordination, duplication and exclusion of some children in need, but the situation is not yet satisfactory as there is no mechanism to ensure that all or most of the affected children are reached.

The World Bank increasingly includes some informal transfer mechanism to support local initiatives for those affected by HIV in the Social Investment Funds (SIF) and Poverty Reduction Strategy Papers (PRSP) it promotes in various countries. If designed appropriately, such interventions may constitute the embryo of a permanent social security system.

While formal systems have many advantages, they need to be adjusted to the administrative, cultural and infrastructural realities of low- and middle-income countries. The Western model of social assistance relies on obtaining detailed information, an approach that would exclude many eligible people in low- and middle-income countries such as South Africa, where large numbers of children have no birth certificate and many grandmothers are unable to qualify for foster grants, as their names are not the same as those of the orphans.

'Best practice' policy responses

Policy context

The situation of children in the HIV-affected societies described in this book demands an urgent response. In some instances, such as in Kenya, the major problem has been the sheer lack of an HIV and AIDS policy (K'Oyugi and Muita 2002). As mentioned by K'Oyugi and Muita, between 1984 and 1989 the government did not consider AIDS to be a serious problem. And the position changed little between 1992 and 1996. Only in 1999 did the Parliament declare AIDS a national disaster and start assigning funds to respond to it. In other cases, the overall public response to HIV is still narrow in scope (generally focused on the 'medical' aspects

of the epidemic) and much less on specific policies in the field of PMTCT, orphan care, or education.

A second, common implementation problem is the disconnect between international institutions and national policies on the one hand, and local-level communities engaged on the front line of the response to AIDS on the other. In most cases, local communities cultivate their centuries-old tradition of self-reliance and the central government is happy to play a passive role. However, social traditions and cultural norms are clearly inadequate to cope with the enormity and complexity of the AIDS challenge and institutional channels between the central power and local communities are only slowly being created.

The majority of governments still see HIV in terms of health and are slow to realize that the social and economic impact of the disease requires broader policy responses and adequate resource allocations. Part of the problem is the somewhat understandable tendency to focus only on those infected and not to extend interventions to the wider circle of people affected indirectly by the disease. As noted by Barnett and Whiteside in Chapter 8, an analysis of the Bukoba district of the United Republic of Tanzania showed that, while 32 per cent of the families had been directly affected by HIV, another 29 per cent had experienced ripple effects due to the obligation to foster orphans, assist survivors or provide labour or cash to help those suffering from HIV-related illnesses.

One of the reasons for the delay in assisting people affected by the epidemic may be that such impacts were until recently poorly documented, surveyed and analysed. This is particularly evident – even in success cases such as Thailand – in the management of the financial, emotional and psychological problems encountered by children orphaned by AIDS. Public policy also needs to deal with the legal and human rights implications of HIV for those infected and affected. Their rights are often violated through loss of inheritance and discrimination. Also, the systemic, if slowly evolving, economic and poverty impact of HIV – particularly on children – has not yet been given serious thought, though some programmes promoted by the World Bank (SIF and PRSP) and UNICEF have recently started to draw the attention of policymakers in this direction.

Health policies

In all countries – those with low/high prevalence, rich/poor, able/unable to manufacture ARV and others – prevention remains the pillar of the overall health policy. It requires strong political commitment (as in Senegal and Uganda) and social mobilization (as in Thailand), as well as clear recognition of the HIV problem and its impact on society.

Information campaigns to change risky behaviour need to be institutionalized and sustained over time, including in countries, (such as Thailand and Uganda) that successfully reduce prevalence. Relaxing prevention efforts could push prevalence

up again. As shown by the experience of Senegal and Thailand, such campaigns have to be mainly focused on high-risk groups and cover rural and remote areas where low prevalence is likely to increase because of growing rural-urban interaction. So far, prevention programmes have tended to be based on an ‘information dissemination model’, predicated on the idea that knowledge automatically leads to changes in behaviour. Future programmes should pay much greater attention to the perceived incentives, attitudes and other factors involved in behavioural change among groups resistant to prevention messages. The school system could play a much bigger role than it has done so far, in order to reach young people at an early age.

Best practice prevention policies also require a strong focus on the treatment of STIs. One of the reasons for Senegal’s success in prevention was the existence of a policy of STI treatment of sex workers before the HIV outbreak even started.

Voluntary testing for HIV has been shown to reduce transmission, but, particularly in areas where ART is not available, people are reluctant to be tested, fearing the stigma and virtual death sentence if they have a positive result. Increased efforts are needed to improve privacy protection counselling and palliative care, as well as extend ART.

In all countries – especially China – secure blood transfusion and proper screening of blood products, as well as appropriate measures for the use of disposable syringes or adequate sterilization, should be introduced.

The initial – but very limited – successes recorded in the field of PMTCT of HIV need to be consolidated and extended. Of the nine country studies analysed, only Thailand and, to a lesser extent, Kenya and Uganda have sizeable programmes under way. South Africa cited financial difficulties and organizational constraints preventing the start of the programme. The cost of PMTCT is relatively low – even for low-income countries. Its benefits are very high, in terms of both lower infant and child death rates, a major problem even in countries, such as Thailand, that have reduced HIV prevalence, and savings on the cost of treating paediatric AIDS cases.

The main constraint to the implementation of this programme is institutional and managerial, particularly in the context of declining budgets and limited coverage of the health-care infrastructure. While three quarters of women receive some antenatal care during pregnancy, less than half have trained staff present during delivery. Implementation of PMTCT of HIV also entails voluntary counselling and testing, followed by antenatal interventions, modified midwifery and infant feeding practices, treatment with nevirapine, free breastmilk substitutes for six months and prophylaxis for opportunistic infections.

In many countries, the spread of HIV has entailed the weakening of the PHC system, though others, such as Uganda, have managed to expand their basic health

infrastructure, despite the HIV epidemic. Chapter 10 shows that as HIV has spread, immunization rates and maternal and child health services have deteriorated in several African countries.

It should therefore be a top priority to strengthen the essential activities of PHC, while at the same time seeking synergies between the treatment of HIV and non-HIV-related ailments, by strengthening activities, such as the Essential Drugs Programme and the district pharmacies, that play a key role in the response to both AIDS and other diseases.

Safeguarding the overall functioning of the health sector: One of the impacts of HIV is to weaken public and private health institutions, both through the deaths of nurses and doctors, and by affecting their morale. Recruitment of adequate members of staff and their training in HIV-focused activities, such as administration of a home-based simplified ARV therapeutic protocol, are needed.

Attention also needs to be paid to the geographical distribution of the health service. PMTCT and ART programmes can only be scaled up if the infrastructure extends to rural as well as urban areas.

Balance between prevention and ART: Before the latest development in ARV pricing, policymakers usually opted to allocate all their scarce health resources to prevention (and palliative care). Selection of the optimal expenditure mix is obviously conditioned by factors such as the level of HIV prevalence, GNP per capita and distribution, the strength of the health infrastructure, the cost and efficacy of prevention and treatment, coverage of health insurance, and the ability to manufacture or import generic antiretrovirals. But it also depends on the choice of policy objective. If the objective is to '**minimize HIV prevalence**', the decision to prioritize prevention is socially optimal. But if the objective is to '**maximize the years of life**' the policy may change. In Thailand, a decline in HIV prevalence was accompanied by a rise in AIDS deaths and in the number of children orphaned by AIDS. Chapter 10 by Cornia, Patel and Zagonari presents simulations suggesting that, if the policy objective is to reduce prevalence, prevention would receive over 80 per cent of total public health expenditure (and ARV less than 20 per cent). But if the objective is to maximize the years of life lived, the proportion spent on ARV would be increased from 21 per cent to 64 per cent (depending on the cost of the drugs) and expenditure on prevention would decrease accordingly.

When doing cost-benefit analyses of ARV treatment costs, policymakers should also take into account the benefits of having fewer orphans and therefore a decreased need for allowances and other support; savings on palliative care and opportunistic infections; and a halt to the slowdown in economic growth (estimated at 0.5 to 1.0 per year in most countries with medium-high prevalence).

Education

AIDS represents the largest single threat to education. Schools are a high-risk environment. One third of the HIV-positive people in South Africa were infected during their school years. Yet, as argued by Coombe in chapter 9, schools can do much to promote the response to AIDS. The educational system should become a far more important instrument of prevention, especially for younger students. This requires substantially increased awareness of, and knowledge about, HIV and AIDS among educators. Pre-service and in-service programmes for teachers need to be adjusted so as to provide training on HIV aetiology, sex education, counselling techniques, ART and so on.

The teachers will also need to learn how to respond to some of the emerging educational problems of the AIDS era. Considerable curriculum adjustment is necessary. In many communities, belief persists that any kind of sexual education leads to increased sexual activity, though studies in Africa show that this is not the case. Sex education should emphasize respect for women and girls, who have often been the victims of rape.

A third policy that should be introduced more widely is the waiving of primary school fees (as in Malawi, Uganda and United Republic of Tanzania) and the introduction of school feeding programmes, though if such programmes are selective, they need to be very carefully designed in order to avoid stigmatizing recipients.

Though there is no evidence that massive AIDS deaths have – yet – crippled the supply of educational services, it has been argued that this may happen in the future in countries that experience a high death rate some years after their high HIV prevalence has started to fall. A related – and even more urgent – problem is how to offset the perceptible decline in education quality due to increased absenteeism, sickness and low morale among teachers. Potential measures include the extension of ART and counselling among sick teachers, the hiring of ‘barefoot teachers’ and multigrade teaching in remote areas.

Children orphaned and abandoned due to HIV and AIDS

A critical challenge is identification of what is ‘best practice’ in the care of children affected by HIV. Several approaches are being tried with varying success in different local circumstances. However, what works well locally may not work as well when replicated on a wider scale.

Some of the problems encountered in introducing ‘best practice’ interventions or in expanding their scale are technical, but others fail because governments may be reluctant to promote them if they implicitly criticize past approaches or lack of action. In chapter 11, Phiri and Webb identify the following alternative care options:

Institutional care: Placing such children in state or faith-based orphanages is seldom the preferred option, except when children have been severely abused or require highly specialized assistance. However, orphanages often appeal to the relatives of poor children because they are perceived to be well funded and thus able to solve children's material needs. Several studies show that the majority of children in orphanages were placed there not so much due to the death of a parent as because of poverty or divorce. These institutions, however, suffer from well-known problems: first of all, their unit costs are high (\$600–\$2,000 per child/year) so that it is impossible to replicate such an approach on the scale required by the current HIV emergency. In addition, institutional care does not provide the holistic care and environment that a family setting offers. As a result, children in institutions lack basic social, cultural and parenting skills, have relational difficulties and have problems adjusting to the outside world when they leave the orphanage. Moreover, they only have tenuous ties with the clans and villages from which they originate. This lack of connectedness is particularly important in Africa and Asia, and is an important component of the personal identity of the child.

Community-based children's homes and orphanages: Such institutions are caring for increasing numbers of children orphaned by AIDS, though firm data are scarce because they are often unregistered. Phiri and Webb note in chapter 11 that the number of HIV-positive children (not necessarily orphans) placed in community-based institutions has increased tenfold in Thailand over the last decade.

Informal fostering: Based on ties of blood, religion, or informal solidarity, informal fostering predominates in many traditional societies of Africa and Asia – but may not be easily scaled up. It needs, in any case, to be supported by some collective action to ensure that it is adequately resourced and externally monitored. But if support is only given to families caring for children orphaned by AIDS, it could be stigmatizing. Botswana has provided funding but has not yet developed the institutional structures to support, monitor and supplement the traditional work of foster families, communities, faith-based organizations (FBOs) and NGOs.

Community-based foster families: Sometimes a foster mother (or a group of mothers acting collectively) takes up to six children in a house provided by the community. The foster mother receives from the state or a large NGO (e.g. Uganda Women's Effort to Save Orphans (UNESO) a child support or foster grant for each child as well as a small allowance for herself. At times, the transfer of foster grants by state institutions faces administrative and eligibility problems, as in the case of South Africa where abandoned children may lack identification documents and cannot easily apply for support. Some administrative simplification is therefore required. With this approach, siblings are kept together and community structures are involved in the monitoring of various foster mothers, in ensuring access to services and – whenever feasible – in providing psychological help and legal counselling to

children. Large NGOs (as, again, UWESO) can provide additional resources for food, school fees (\$35 a year for primary school and \$75 for secondary), health costs and clothing. When these resources are scarce, the communities prioritize the neediest children.

The limited evaluations available tend to show that institutional care is the most expensive and least appropriate solution, and that formal or informal community-based foster care are most effective, not only in terms of cost efficiency and replicability, but also as a way of providing essential affectionate care for the children. Yet, these local fostering models often do not meet even minimum standards of resources, supervision and stimulation. Thus, the success of community fostering crucially depends in many cases – and particularly so in poor communities – on receiving external support in terms of money, supervision, counselling and so on. As mentioned, the two main sources of support can be the government and NGOs. So what particular role can NGOs fulfil in low-income societies with weak bureaucracies?

One of the external supports required is that of ‘informal visiting social workers’. Foster families face more financial and psychosocial problems than normal families and need to be supported from outside. A good experience in this area is that of FOCUS, a Zimbabwean NGO that works in close contact with community leaders. All orphans in a given area (regardless of their family arrangements) are counted by this NGO (see chapter 11). In addition, trained volunteers (widows or women already caring for orphans) visit them at least twice a month, provide them with resources and emotional support and monitor the material and psychosocial situation of the children. The visiting volunteers make sure that the typical problems affecting orphans (school dropout, ill health, isolation and stigma) are avoided and – when needed – provide essential material support in the form of blankets, food and school fees.

Another way of helping from outside consists of offering ‘overall intersectoral assistance’ to communities caring for large numbers of orphans. Malawi’s COPE programme (Community-Based Options for Protection and Empowerment) tries to catalyse community energies in four areas: orphans, youth, prevention and home-based care. Its work focuses on the identification, monitoring and protection of orphans through programmes such as direct transfers to vulnerable and transient poor, school fee assistance, training, income-generation programmes and other forms of multisectoral assistance chosen by the communities. COPE covers 12 per cent of Malawi’s districts and aimed to cover the whole country by 2006.

The psychosocial needs of orphans and HIV-affected children are often neglected. HIV causes not only death, hunger and other material deprivation among orphans, but also a sense of abandonment, depression and rejection. Children do not verbalize their feelings. They may become withdrawn, play truant, antisocial and prone to depression in adult life. Older children may get into conflict with their

foster parents, become aggressive and join gangs of street children. In several cases, entire cohorts of young people will grow up in situations in which mental ill health will be rife.

Responses in the form of counselling, role models and education through work are not intrinsically complex but they need to be applied on a scale never confronted before. And this is where the work of foster mothers and community parenting needs to be integrated with specialized external help. Structure, predictability and stimulation with traditional games are three important components of any programme aiming at reducing psychosocial stress among orphans.

Economic support and welfare transfers to impoverished families

Economic support: How to fight the long-term depressive effect of HIV on the economy, and the subsequent impact on higher HIV prevalence, reduced access to health care and child poverty? HIV generates an imperceptible but deepening shock that gradually erodes the stocks of skilled and unskilled labour, land fertility, financial savings, investments and social capital. Therefore, policies aimed at sustaining economic growth and avoiding poverty should be focused on preventing the decline of these productive resources. This clearly entails not only prevention of HIV, but also ART, particularly for those workers whose replacement cost is higher than the cost of the drugs.

If treatment of the workers is impossible, there is a need to accelerate the training of potentially scarce workers, the loss of whom could have a significant negative impact, as in the case of people running power grids, water and railway systems, health facilities and schools. Thus, ‘best practice’ policy requires budgetary support for training (or importing) such specialized workers. Targeted interventions in these sectors can avoid slowdowns in growth. There is already scattered evidence that communities affected by HIV adopt less rigid forms of division of labour by skill level, age and gender and encourage labour pooling arrangements, especially in agriculture.

Overall anti-poverty measures: In chapter 7, Cornia and Zagonari argue that HIV impoverishes not only the person infected but also – through demand, supply and other systemic effects – those connected to him or her. One way to fight these effects is to introduce employment-based programmes to sustain the employment and incomes of the families affected while avoiding a deterioration of the community infrastructure. Interviews with HIV stakeholders in Phayao, Thailand clearly show that more jobs were required for patients with HIV-related illness. There is already considerable experience with the design and management of such programmes, as suggested by the successful experience of Botswana’s Labour-Based

Relief Programme. The need now is to adjust the design of these programmes to the situation of HIV-affected communities.

Public work programmes are, however, not suitable for families that have no surplus labour. In this case, the objective is to increase the productivity and earnings of the limited labour power available. This can be achieved through micro-credit or skill upgrading programmes. Training in activities where new skills generate quick returns, as well as greater access to funds, enhances the ability of families and communities to respond to AIDS, as shown by various projects carried out in Eastern and Southern Africa, often with the participation of large NGOs. Borrowing may create short-term liabilities and therefore these programmes may not be suitable for persons diagnosed with AIDS (who may be weak and unfocused) though they might be attractive to their family members.

Broad family-focused income transfers will be necessary for those affected families that cannot be helped through employment-based microcredit and training programmes. Besides the targeted child and orphan allowances discussed earlier, there are examples in low-income settings of low-cost, non-contributory, state-funded schemes that avoid the erosion of community self-reliance and altruism and provide coverage against the risks of poverty, sickness, disability and widowhood. In India, the Kerala and Tamil Nadu non-contributory old age pension schemes are two good examples of such programmes (see chapter 7). The design of such transfer programmes is essential for their success, particularly as it concerns the value of the benefit (in Phuket, Thailand, the people living with HIV (PLHIV) interviewed mentioned that the 'intrusion cost' was too high in relation to the small amount of the transfer received), the administrative arrangements adopted for the transfer of the funds, the selection of the eligible families and accountability mechanisms. As for the administrative arrangements, the obvious choice is a competent, honest and inclusive central and local bureaucracy. Where this does not exist, Phiri and Webb (chapter 11) suggest it might be best to rely on federations of accountable umbrella organizations working with children, such as multilayer committee structures, national funds and faith-based organizations.

The political economy of the response to AIDS

One of the main reasons for the limited success in the response to AIDS is the limited commitment of most governments to fight the spread of the disease and to mitigate its impact. Most HIV-affected countries have been accused of lacking political will and commitment to respond to AIDS. However, as is well known, this has not always been the case. Countries such as Senegal, Thailand and, to some extent, Uganda were able to control adult prevalence at low levels or to reduce its level after an initial rise. What explains, then, the openness and directness with which the AIDS problem has been dealt with in some nations, while in others with

similar structural characteristics the AIDS problem has been denied, ignored or trivialized? And, why have some countries allocated substantial resources to the control and mitigation of the long-term effects of HIV, while in others the burden of responding to the epidemic has been shifted to families and communities? Do these differences depend on the structural characteristics of the countries concerned? Or on the different perceptions of self-interest by the elites? Most explanations of the differences in policy concern the presence or absence of charismatic leaders. But these explanations are not very convincing.

A first observation is that governments usually act in response to their perceived self-interest. The first possible explanation of inaction when dealing with HIV is that the elites have only vague information on the nature of the disease, its spread and impact on the various social groups and on the fact that the entire social system may collapse because of it. In this explanation, inaction depends on ignorance of the facts. Also, even when information on the disease is available, there is likely to be a time lag before there is a coherent response.

A second explanation is that the political elite is informed about the epidemic but the situation is so overwhelmingly negative that the leaders resort to denial and inaction. Another reason for lack of action could be that, although the political leadership is well aware of the risks, it has no interest in intervening because the groups affected belong to racial, ethnic or social minorities. This model ('they, not us') is well tested and can explain why the elites do not act unless they feel they might be affected themselves.

A fourth possible cause of weak and delayed interventions by governments is that those who should act have an incentive in preserving the status quo. Especially in the early stages of the infection, many local governments do not want to know about HIV and, indeed, do not want others to know for fear it will reflect negatively on their locality or on its officials. Also, when HIV prevention requires control of risky behaviour such as sex work, local officials may be reluctant to enforce new regulations that might decrease their income.

As suggested by Amartya Sen, democracy and a free press should in principle facilitate action against HIV (as well as famine). The democratic process allows citizens – including those affected by HIV – to pressurize their governments to act swiftly against the disease. In Senegal, parliamentarians were expected to work for the campaign against HIV during the state budget. In Thailand, the establishment realized that HIV was a major social problem relatively early on. This led to the creation in 1991 of the National Aids Commission, a policy-making body chaired by the Prime Minister that oversees a multisectoral anti-AIDS policy, involving the private sector, NGOs and local communities as well as the government.

A committed and competent bureaucracy and cohesive civil society are essential for the success of any collective undertaking. In China, the dismantling of the

public health services, ineffective STI control and the difficulties in communicating between central, local and village authorities proved to be major obstacles to an early and effective national response to the epidemic.

Faith-based groups – who maintain a strong influence in traditional societies – seem to have played a key role in the response to AIDS. Although initially opposed to HIV prevention measures, pastors, priests and imams in Côte d’Ivoire and Kenya participate actively in most local-level initiatives, and in Senegal, Thailand and Uganda, faith-based authorities have consistently supported the response to AIDS.

References

- Giovanni Andrea Cornia (ed). 2002. *AIDS, Public Policy and Child Well-Being*. Preliminary version. Innocenti Research Centre. Florence: UNICEF.
- K’Oyugi, B. and Jane Muita. The Impact of a Growing HIV/AIDS Epidemic on the Kenyan Children. In Giovanni Andrea Cornia 2002.
- Pégatiénan, J.H. and D. Blibolo. 2002. HIV/AIDS, Lagging Policy Response and Impact on Children: The Case of Côte d’Ivoire. In Giovanni Andrea Cornia 2002.
- UNAIDS. 2004. *2004 Report on the Global AIDS Epidemic*. July 2004. Geneva: UNAIDS.
- UNAIDS. 2005. *2005 Report on the Global AIDS Epidemic*. Geneva: UNAIDS.
- Verma R.K. et al. 2002. HIV/AIDS and Children in the Sangli District of Maharashtra (India). In Giovanni Andrea Cornia 2002.