Chapter 1

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

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Summary: During the last decade HIV/AIDS has seriously hindered in the some 40 countries with adult prevalence rates above 1 percent the achievement of most child survival and development goals established at the World Summit for Children in the early 1990s. In countries with medium to high prevalence rates, HIV/AIDS has more than wiped out the child mortality gains realized during the 1980s. The prospects for the future are not encouraging, as in some twenty countries adult prevalence rates and U5MR are expected to peak only around the middle of the next decade and as tensions in the educational sector will grow in intensity. Low coverage of antiretroviral treatment means also that the number of AIDS deaths and orphans will continue to rise even in countries with declining prevalence rates. Finally, the global wellbeing of children will depend on the trends underway in large countries such as China and India. While prevalence rates in these countries are still less than one, there is evidence that the epidemic has now entered an exponential growth phase that will cause a worsening in child wellbeing over both the short and long term.

The paper reviews also 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 problem of 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 appears now limited. Indeed, even the countries that successfully reduced adult prevalence rate, are now confronted with a rise in the number of paediatric AIDS cases, AIDS deaths among parents and orphans.

In the absence of more decisive and broader policy action, the prospects of child wellbeing will remain problematic. A broader policy approach to the fight against AIDS is necessary and feasible though even in the best of possible worlds some of the negative effects of the disease will continue to be felt over the long-term. The chapter ends discussing best practice policy and program measures that would help protecting the wellbeing of children in a world affected by HIV/AIDS. So the first step is to stop pretending that progress is being made against AIDS. Better to recognize that so far little has been done to confront it effectively.

JEL: I10, I28, I31, J13

* This study presents the views of its author and not the official UNICEF position in this field.

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AIDS, PUBLIC POLICY AND CHILD WELL-BEING *

edited by Giovanni Andrea Cornia

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1. Context and focus

The broad facts about the HIV/AIDS epidemic are known to everybody: 40 million people are now infected world-wide, and over 20 million people have already died from AIDS since the beginning of the epidemic in 1981. Three million people died in the year 2001 alone. 95 percent of people infected with HIV live in developing countries, primarily sub-Saharan Africa. While HIV prevalence has started declining in a limited number of countries, in several others adult prevalence is expected to peak around 2005, while there is a risk that the contagion could spread rapidly in the years ahead in Russia, China and India where prevalence rates are still fairly low but are now rising at an alarming rate. With the prospects for the development of an AIDS vaccine still uncertain, it is clear that the battle against HIV/AIDS is all but won.

Interestingly, while this broad picture is well documented and widely appreciated, the same cannot be said about the impact of HIV/AIDS on children. Strangely enough, while there are excellent statistical works and analytical contributions in some problem areas (e.g. orphans) or programmatic responses (awareness campaigns for the youth or PMTCT) broad-based assessments of the impact of HIV/AIDS on children are few and far between. For instance, updated information on the impact on the most basic indicators of child well-being – the Infant Mortality Rate (IMR) and Under 5 Mortality Rate (U5MR) – is not readily available, and the same applies to the number of paediatric AIDS cases or to the impact on enrolment rates. This is due perhaps to the perception that, by affecting mainly young and middle age adults, the epidemic would have spared children. Or to the fact that statistical sources in most affected countries are week.

Be as it may, this overall study attempts to fill in part this knowledge gap and this chapter offers an overview of the impact of HIV/AIDS on children and the desirable policy responses on the basis of the evidence provided by the case studies and analytical contributions included in this study and of the literature in this area. Such broad-brush overview leads to a few preliminary observations that are presented hereafter and will be elaborated in the continuation of this chapter:

- the first is that for the children of the families affected, the impact of HIV/AIDS is consistently and clearly devastating, with no exceptions. But at the macro level, i.e. at the level of national averages for child wellbeing indicators, the impact starts to be perceptible when the prevalence rate exceeds 3-4 percent. In countries with prevalence rate around 2-3 percent (Thailand, Ghana, Mali and Benin, for instance) 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 succeeds in controlling HIV prevalence, it might not be equally successful in terms of AIDS deaths, number of orphans, child poverty, and the care, socialisation and emotional development of a growing number of orphans and abandoned children;

- when the deterioration at the macro level is evident, the sectoral effects are not uniform and do not share the same time profile. The first impact to be felt concerns the quality of education, infant and child mortality, and perhaps child nutrition (though evidence in this field is limited). The impact on teachers' absenteeism, contact time and morale is also rapid. So it is that on the 'crowding out' of non HIV/AIDS patients from the public hospitals. The same can be said also for IMR and U5MR that respond fairly quickly to a rise in HIV prevalence among pregnant mothers as, sadly, the survival time of an untreated HIV positive new-born is on average of 2.2 years. In contrast, the rise in the orphan rate, the possible collapse of education due to increased AIDS deaths among school staff and the overall impoverishment of families and children due to an AIDS-induced drop in economic growth are instead slow to take effect – as they depend on the death of a good number of parents, teachers and workers, an event that requires time to materialize. And some effects of the epidemics - such as those related to the long term effects of the emotional deprivation and ill mental health of the 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/AIDS on children is still ahead of us. This is clearly visible in high-prevalence South Africa where the prevalence rate is expected to peak around 2005 as well as in China and India. In both countries, the epidemics is still in its inception, with nation-wide adult prevalence rates estimated at around 0.2 and 0.8 percent but in the absence of timely and decisive interventions the epidemic could spread rapidly. These countries do not seem to have learned from the experience about prevention and mitigation of countries such as Thailand and Senegal. In China, for instance the number of HIV positive people has risen exponentially since 1993 in parallel with the increase in STD. By 2002 it reached close to a million people, a number that in the absence of a strong intervention could reach 5 million by 2005 and 20 million by 2010.

2. 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 preventing at its root the occurrence of the phenomenon. What are then the main correlates of HIV?

- (i) bio-medical factors. They include the prevalence of sexually transmitted diseases (STD), poor health and nutritional status, male circumcision and sexual behaviour. Level of treatment of STD are often low because the disease tends to be asymptomatic. STD levels have a large impact on the risk of contracting HIV. Chapter 6 on Kenya, for instance, shows that people with STD were found to be up to four times more likely of contracting HIV during sex than those without. Wounds and ulcerations on the genitals act as avenue through which the HIV virus can easily enter into the blood system. Male circumcision in turn reduces the risk of contagion.
- <u>Sexual habits</u> are obviously an important predictor of the risk of contracting HIV. The frequency of intercourse, number of partners (including sex workers), types of sexual practices, extent of condom use, knowledge of partner's HIV status and resistance to change are the main determinants of both hetero and homosexual

transmission. This is most obvious among the sex workers, the Indian devadasis and IDU

- In China the <u>over-use of curative injections</u> (and tattooing) is another source of contagion. It is estimated (see chapter 9) that children below 5 receive on average 6 injections per year, a fact that certainly contributes to the spread of hepatitis B and to the transmission of the HIV contagion. About half of curative injections in China are unsafe because of improper sterilisation and unsafe injection practices.
- paid plasma and blood donations. In parts of China the sale of blood is a common survival strategy adopted by the poor who repeat this operation several times a month for a fee of 5 \$. Blood from people from the same blood type is pooled and centrifuged to separate the plasma, which was then sold. The remainder of the pooled blood is re-injected into the farmers. As a result, one million people got infected in the Henan province alone. In extreme cases, as in blood donor villages in Hebei and Hubei, up to 62-75 percent of the people selling their blood tested positive. An October 1998 law banned blood donations for money, but chronic blood shortages, money incentives for the poor and lack of information about HIV make it more difficult to eliminate this phenomenon.
- (ii) social risk factors. A first factor is high spatial mobility caused by temporary migration, forceful displacement (as for refugees and IDP) or the characteristics of professions involving the protracted absence from the family (as in the case of truckers, fishermen, soldiers, contract labor working on construction projects, sale-representatives, tradesmen, seasonal workers in commercial farms). Truckers seem to be particularly at risk. In Zimbabwe, in 1996, 30 percent of the staff of a major transport company was HIV-positive. A study of a rural community in Kwa-Zulu 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 7, Janjaroen and Khamman show that migration from poor neighbouring areas of Burma and Cambodia are a possible factor in the recent upsurge of HIV prevalence in Thailand. Even in low-prevalence Senegal (see chapter 4) HIV/AIDS prevalence rates of 23 percent were reported among the adults of villages characterized by strong prior emigration.

Domestic migration leads to rapid urbanisation which is often associated to the spread of STD 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 likely been facilitated by the massive internal migrations that involved a 'floating population' of over 100 million people. Local surveys from Shanxi show for instance that of the people that had been found positive, two third were migrant workers (see chapter 9).

- <u>Location</u>. HIV prevalence rates are generally higher in urban than rural areas as the chance of contact with high risk groups are generally lower. Yet, there is evidence that such urban—rural gap may be inverted over time as prevalence may fall in urban areas (e.g. because of information campaigns) while rural areas may catch up. As suggested in chapter 5 by Pégatiénan and Blibolo, the rural areas of Côte d'Ivoire provide seasonal manpower to urban areas who act as a source of contagion in rural

areas because of frequent return journeys. The periodic trips to urban areas by youth associations are an additional source of possible contagion.

- The incidence of HIV varies also according to <u>social status</u>. Jobs that give social status and power as in the case of army and policy (as in Yunnan, Thailand and Cambodia) and wealthy managers also exhibit rates of infection higher than the average for males (but not for women). Teachers and health workers enjoy both social status and often live away from their families. This exposes them to higher risk of engaging in sex with multiple partners.
- income level and distribution, poverty, unemployment and marginality raise the risk of contagion in urban areas. Poverty and uncertainty about the future, for instance, lead to short-term survival strategies characterized by risky behavior. Unemployment and social exclusion, in turn, have key factors in IDU epidemics. High income inequality tends to affect also the cohesion of local communities and to reduce their cooperative behavior.
- the empowerment of women in terms of employment, incomes and social roles tends to reduce the risk of contagion. Reducing discrimination against women in these areas increases the women's independence and their ability to negotiate sexual contacts at their own terms. This would benefit in particular 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 (chapter 3) seems to confirm this finding.
- <u>education level</u>. In the first stage of the HIV pandemic, educated men were particularly hit by HIV as their status allowed them to entertain multiple sexual relations, 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 epidemics has now shifted to people with low education and ability to absorb messages about prevention.
- (iii) cultural norms. Cultural and religious norms and beliefs such as attitudes towards early-, pre- and extra-marital 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. In chapter 3, K'Oyugi and Muita show that the risk of becoming HIV positive among Kenyan women varies with their marital status. The risk is significantly higher among women in polygamous than monogamous marriages. And it is 3 times as high among widows.
- (iv) political events. Areas such as the Great Lake Region 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 owing to transactional sex to secure life, high rate of partner change, alcohol as substance abuse due to frustration and idleness.

3. Changes in the wellbeing of children in countries affected by HIV/AIDS

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

3.1 Changes in infant and child mortality over the 1990s

(i) overall impact. In Chapter 13, Cornia, Patel and Zagonari show that in the 1990s U5MR mounted rapidly in 8 countries from Southern and Eastern Africa with high HIV adult prevalence rates and pre-AIDS coverage of child health services. Child mortality increased also 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 percent but in Botswana it reached 80 percent. In this country, in the 1990s HIV/AIDS more than erased all gains in child mortality achieved during the 1980s. On a sample of 40 countries, a one percent increase in HIV adult prevalence raises U5MR by 1.9 points per thousand. HIV/AIDS may have been responsible also for the slower-than-the-trend decline in U5MR in a few countries (Benin, Burkina Faso, Ghana, Dominican Republic and so on) with low-moderate HIV prevalence and a steady expansion of health services for children. In contrast, in some ten countries, the moderate surge in AIDS-related child mortality was more than offset by a drop in child mortality for other causes owing to an expansion in immunisation coverage, delivery care and other health interventions. Because of their initial 'backwardness', these countries benefited from the 'basic health services dividend' in the era of HIV/AIDS

In several countries, the unfavourable trend in U5MR will continue in the years ahead. For instance, in South Africa it has been estimated that U5MR will grow from 95 to 110 per thousand between 2001 and 2006. In Kwa-Zulu Natal, the most affected province, it is expected to exceed 140 per thousand in 2006, more than double the rate for 1992 (see chapter 6).

The observed rise in U5MR can, in principle, be attributed to three set of factors. First, infants borne to an HIV positive mother have a 25 to 45 percent probability of being infected by the virus, contracting AIDS and dying in 1-3 years from birth (see next point). 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 the expenditure on immunisation and other health programs for children. Table 6 in Chapter 13 provides evidence of the decline in immunisation rates and other basic health programs in the 1990s, though this may have been caused by factors other than AIDS. Evidence from Côte d'Ivoire (chapter 3) and other studies suggest that the 1990s witnessed a resurgence in the number of cases of malaria, diarrhoea and malnutrition. While available data does not permit to establish a

conclusive relation between the HIV epidemics and these changes, the compression of PHC and increased pressure on secondary and tertiary care generated by AIDS might be a contributing factor.

In addition, the surveys undertaken as part of this research project show that children in families in which the head of the household died of AIDS had a distinctly higher risk of death of children in families where the head of the household died for some other cause or where there was no death. This evidence is clearly born out by the survey of Sangli, Maharashtra (Chapter 8), the Côte d'Ivoire sample (Chapter 5) and the Ugunja Division of the Siaya District in Kenya (Chapter 3). In the latter case, for instance, the child mortality rate in the families affected by AIDS over the 18 months preceding the date of the interviews (May 2001) was 16.7 percent in relation to about 5 percent in the two control groups. The same surveys show that one possible explanation is the reduced access to health care in AIDS affected families (Table 1).

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

	HIV/AIDS death	non HIV/AIDS death	No death		
Sangli, Maharashtra	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 on data provided in the case studies included in this compilation

Third, mortality among children may rise also because of the AIDS- induced impoverishment of the family in which the child lives. Table 1 in Chapter 10 shows in fact that the average income of the families whose head died by AIDS during the prior 18 months drop by up to 40-50

(ii) increased mortality due to paediatric AIDS. In 1999 alone, 570.000 infants worldwide became infected, bringing their total number to 1.2 million. Of the nearly 4.8 million children so far infected with HIV since the start of the pandemic, 90 percent were born in Sub-Saharan Africa. Vertical transmission accounts for over 90 percent of the paediatric AIDS cases, while the remaining children contract the virus from contaminated blood products or contact with non-sterile skin-piercing instruments. Most studies suggest that the probability that the baby of an HIV-positive woman to be positive range from 15-25% in the industrialized countries to 25-45% in developing countries. As noted by Phiri and Webb in chapter 15, a study in Uganda found that roughly a third of HIV-positive children died in their firsts year, half died by 21 months and three quarters after five years. Similarly in Malawi, some 90 percent 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.

Lack of data on the incidence of paediatric AIDS does not allow to isolate precisely the impact of vertical transmission from that of impoverishment and reduced access to health care – though simple arithmetic and anecdotal evidence show that most (but not all) of the observed increase in U5MR is to be attributed to the rise in HIV prevalence among pregnant women. In South Africa, for instance, already in 1997 half of the admissions to paediatric wards were due to HIV. In areas of the country with very high rates of infections up to 75 percent of the beds in children wards are occupied by children with HIV conditions. This finding provides a strong rational for stepping up programs to provide universal coverage of nevirapine to the newborns.

Indeed, while immunisation, oral rehydration therapy, 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 HIV adult prevalence. Chapter 13 shows, for instance, that a ten percent rise in HIV adult prevalence more than erases a similar expansion of DPT, fresh water supply, ORT, delivery care and breastfeeding 0-3.

3.2 Changes in child nutrition

Information in this area is less than in that of mortality. In principle, HIV/AIDS 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. Second, the large decline in incomes suffered by families with a AIDS death (Chapters 10 and 11) impose 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, for instance, that the practice of reducing food diversity has increased among HIV affected families but not among the others, and that 32 percent of the former adopted could count on a little diversified diet in 2000-1. 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

	HIV/AIDS death	non HIV/AIDS death	No death
Sangli, Maharashtra	35.5	44.0	5.0
Ugunja, Kenya	30.6	29.4	26.7
Côte d'Ivoire	27.0	23.8	11.3

Source: author's compilation on data provided in the case studies included in this compilation

Third, malnutrition among unaffected children may rise as well. In Chapter 15 Phiri and Webb show that children of families taking in orphans experience lower nutritional levels as the scarce family resources available are redistributed among a growing number of children.

3.3 Changes in educational achievement

(i) 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 largest declines were observed in HIV affected countries such as Kenya, Tanzania and South Africa though other HIV-affected countries were unaffected or – as in the case of Uganda – recorded steady improvements in enrolment rates. These trends are confirmed by the evidence presented in this study. In Chapter 6, for instance, Desmond and Gow illustrate the rapid decline in primary enrolment rates (from 130 to 86 percent) recorded in South Africa as a whole over 1995-97 and the recent and equally large drop recorded over 1998-2001 in KwaZulu Natal. Similar aggregate trends are provided by the chapters on Kenya and Côte d'Ivoire but not in Uganda and Thailand, let alone in low-prevalence Yunnan and the Sangli district.

At the aggregate level, the relation between HIV/AIDS and educational achievements is therefore far from simple owing to the influence of economic recessions, conflicts and shifts in educational policy. In contrast, at the individual level the relation between HIV/AIDS and enrolment rates is fairly clear. The well-known World Bank study on Kagera (Tanzania) shows, for instance, that the enrolment rate of children of 7-10 years of age in non-AIDS families was 44 percent while among affected families it was 28 percent. Similar results are found in this study (see Table 3) that point to higher dropout rates among AIDS orphans. The analysis of the Kenyan data in Table 3 by K'Oyugi and Muita (Chapter 3) shows, however, that the risk of withdrawing one's children from school in AIDS-affected households declined with the rise in the level of income.

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

	HIV/AIDS death	non HIV/AIDS death	No death	
Sangli, Maharashtra	4.3	4.6	2.6	
Ugunja, Kenya	23.9	19.1	14.8	
Côte d'Ivoire	27.7	18.5	16.0	
Rural South Africa*	14.0	•••••	6.0	

Source: author's compilation from the case studies included in this compilation.

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 5) suggest a less pronounced but still worrying tendency as six percent of the adults declared that as result of HIV at least one of their children was dismissed from school. In addition, children with AIDS may have faced problems of integration and, although there were no systematic discrimination was observed in schools, they were more likely to attend Koranic schools that are normally considered a lower quality substitute for public education.

Finally, the data from Uganda suggest that public policy can help in expanding massively enrolment rate amidst a severe AIDS crisis if the educational policy – that raised substantially the number of new schools and primary and secondary teachers and abolished school taxes to achieve Universal Primary Education to the Year 2000 – deliberately focuses on expanding educational opportunities. The message seems to be clear: while AIDS affects substantially both the demand and supply of education, educational policy can minimize its impact and sustain progress in several aspects of education.

(ii) quality of education and other related issues

HIV/AIDS affects also the quality of educational services. Teachers are lost through death, attrition and transfers In Zambia, Malawi and Namibia, HIV infection rates of up to 40 percent have been reported among teachers. Even assuming their timely replacement, the quality of education will be affected, as the new teachers entering the educational system will lack the experience of the older and more experienced teachers decimated by AIDS. The observed concentration of teachers' deaths in the 30-39 years age group, just when the teachers had accumulated important experience, will mean a considerable loss of expertise. AIDS-related illness also means that educators become less productive. Sick teachers are affected by low morale, frequent absences, reduced contact times with the students and difficulties in concentrating in the face of illness, death, mourning and dislocation. In Côte d'Ivoire, for instance (see chapter 5), 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 for instance, children from AIDS-affected families who remained in school had frequently to miss class (due to their involvement in domestic duties), obtained poor results, and faced difficulties in buying school stationary. As Coombe notes in chapter 12, all this adds up to a school environment characterized by distress, anxiety and confusion and lower teaching efficiency. Unless of a strong policy response, the quality of education is bound to fell in such an environment.

3.4 A rising number of orphans

(i) AIDS orphans. UNAIDS estimates that the number of AIDS orphans reached 13 million at the end of 2000 and will rise to 24. 3 million by 2010. However, as argued by Phiri and Webb in Chapter 15, this figure grossly underestimates the true scale of the problem as it does not include the paternal orphans, the orphans aged 15-18 and the 'social orphans'. In their view, more realistic orphans figures would be 34.6 million in 2000 and 44.7 by 2010, i.e. a number 2 to 3 times larger the UNAIDS estimate. When expressed in percentage terms, the orphans problem appears even more frightening. In a developing country with no AIDS, the orphan rate among children of 0-18 years is of around 2 percent. But in the 34 countries most affected by AIDS, such proportion had risen by 2000 to 10.9 percent, with peaks of 27.4 percent in Zambia and 25.7 in the Central African Republic. By 2010 it is expected to reach an average of 12.6 while in Botswana, Namibia and South Africa it will range between 30 and 36 percent, a tragedy never observed in known history, not even during the Black Plague that hit Europe between the 14th and 16th century.

In China and India, the problem is and will remain much more limited, not least because of the lower fertility, at least over the next ten years. In Yunnan, for instance, the number of AIDS orphans is expected to rise from some 2000 to 21.000 by 2010. While this is less threatening than in other countries, this rise is very sharp and will still pose considerable problems because of lack of institutions and policies in this area.

From a time perspective, it is important to stress that of the AIDS orphans is a long wave problem that will last well after the reduction of the HIV prevalence rate, the 'benchmark' used by many policy makers to assess the intensity of the AIDS pandemic. Indeed, the 'orphan epidemic' is still in its infancy and is expected to grow to devastating proportions over the next 10 years. For instance, while Thailand has started reducing her HIV adult prevalence rate since 1995, the number of orphan children has risen from some 20.000 in that year to 126.000 in 2002 and to an estimated 160.000 by 2005. With rates of HIV prevalence still on the rise in the majority of countries, the AIDS orphans problem will be with us for at least 2 more generations.

Orphan children do face a long series of material deprivations. As shown by the data in Tables 1 through 3, children growing up in families with infected, weakened and dying parents 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 AIDS orphans would face an uncertain future and a considerable affection and socialisation deficit. In the best of circumstances, the death of the parents means that they have to live with relatives or in orphanages, face emotional deprivation and psychosocial stress and possibly suffer from ill mental health. They may also become more aggressive, represent a menace to society, commit crimes, turn to drugs or become sex workers. The emotional, psychological and mental damage suffered by these children is slow in being recognized and the related emotional, socialisation and mental health problems are still to be addressed.

One of the most significant impact of HIV/AIDS on orphans is not only the collapse of his or her family but the disintegration of the traditional social arrangements, support structures and social relations at the basis of his or her life. They also face mounting stigmatisation in school in the villages were they live and often create alternative socialisation structures to respond to this situation. In Malawi, as a result of stigma and social exclusion, AIDS orphans tend to form their own informal peer groups. Even in a low prevalence location such as the Sangli district of Maharashtra (Chapter 8), AIDS orphans are strongly discriminated by their peers (Table 4). Orphans also have to assume prematurely and adult role.

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

	HIV/AIDS death	non HIV/AIDS death	No death
Sangli, Maharashtra	20.1	2.8	3.1
Ugunja, Kenya	6.8	1.8	1.8

Source: author's compilation from the case studies included in this compilation.

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.

(ii) social orphans: children abandoned by AIDS impoverished parents. That of social orphans is another indirect effects of HIV/AIDS. With mounting poverty, distress and social fragmentation, many living parents deliberately abandon their children as they feel no longer able to care for them in the new difficult world brought about by AIDS. Positive mothers, in particular, are afraid of poverty and fear stigmatisation. A shown in Chapter 7, in Thailand, the probability of being abandoned by a HIV positive mother is five times that of non infected mothers. And as noted by Desmond and Gow in Chapter 6, with mounting poverty and stress, over the last three years there was a 67 percent increase in the number of children abandoned in hospital wards. This trend is corroborated by the sharp increase in the number of street children coming to shelters over the last few years. And in Swaziland, the number of social orphans now exceeds that of natural orphans (the USAID estimate of the total orphan rate is 15 percent) (personal communication by officials of Swaziland, Lusaka Seminar on AIDS Orphans 2001).

3.5 Economic decline and child poverty.

The literature reviewed in chapter 10 by Cornia and Zagonari suggests that the economic impact of HIV/AIDS depends on the period, prevalence rate and type of country considered, but that in low income countries with medium to high prevalence

rates, the epidemic causes a decline of 0.5-1.0 percent in the annual GDP growth rate. Model simulations presented in Chapter 3 confirm this prediction and suggest that over 2000-2010 the Kenyan GDP will be 14.5 percent lower than in the basic non-AIDS scenario. Table 1 of Chapter 10 suggests also that families that lost the head of household due to AIDS experience a 30-40 percent decline in household income over the subsequent year in relation to the control group. In South Africa, as affected households are generally larger than the non affected ones, their decline in adult equivalent income is often 40-50 percent lower than that of non affected households. While there is evidence that affected families manage to reduce this income gap in the following two years after the death of the head of household, the impoverishment effect lasts several years.

The decline in GDP growth is therefore likely to throw an increasing number of children into poverty, a situation which will not allow them to satisfy several of their basic needs and that will require governments to step up massively welfare payments to poor children, women and elderly. Chapter 6 estimates that in South Africa of the 17 million children, 12 are classified as living in poverty – several of them in families with one or two parents HIV positive who will eventually will develop morbidity and die. Symptoms of growing poverty emerge also from other sources. In Senegal, for instance, the number of power cuts among HIV/AIDS affected families for non-payment of electricity bills increased from 4.5 to 12.6 percent over 1996-2000. Also, the number of street children increased everywhere and so has the number of working children in affected families, though the survey data undertaken as part of this study suggest that child labour increased more within the family than for the market.

4. HIV/AIDS impact on the supply of social services

One of the many impacts of HIV/AIDS has been on the public infrastructure providing basic social services. While these services cover the entire population, in a developing country context, they are especially central to the wellbeing of children. Most commentators stress that the impact of HIV/AIDS in this area has been negative, though two of the case studies included in this compilation stress also its positive effects in the health sector. Positive effects are evident, for instance, in the increase in health educators who prevent and treat both AIDS and non-AIDS-related diseases. Likewise, the desire to prevent the vertical transmission of HIV has led to improvements in obstetric services. And finally, the new procedures introduced for the screening of blood and sterilisation procedures have improved the reliability of these services

4.1 Health Care.

In Chapter 13, Cornia, Patel and Zagonari found that, by generating a large increase in the overall burden of disease, HIV/AIDS crowded out the health resources assigned to the care of traditional sicknesses. It has also directed most of the additional demand for care at the secondary and tertiary levels causing in this way a congestion at these levels while weakening primary health care, including the programs targeted at children. In Côte d'Ivoire the chronic under utilization of health centres and overuse of hospitals were exacerbated by HIV/AIDS. However, 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 STD produced a considerable increase in attendance at peripheral health facilities.

Chapter 13 found also that HIV/AIDS generated a substantial increase in health expenditure that was financed by the households in poor countries (see table 5 of Chapter 13) and by the public sector in most middle income countries such as Brazil, Mexico and, to an extent, Thailand. 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 bigger than that of non-affected families (Chapter 4). In addition, affected families paid two to seven times more than other patients in consulting marabouts.

While the public expenditure on HIV/AIDS is difficult to measure as its absorbs a proportion of the regular health budget, in most countries (Brazil is an exception), the budget allocations to AIDS remained modest both in absolute term, as a share of public health expenditure (Table 5) and of GDP, thus ridiculing the view about the massive drainage of public resources caused by AIDS. In Thailand, for instance, the AIDS budget has oscillated over 1992-2001 between 30 to 60 million \$, which is to say a minuscule 0.02 to 0.04 of the national GDP and 2-3 percent 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
C. 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/AIDS has eroded the delivery capacity of the whole health sector due to mounting infection rates and AIDS deaths among the 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 (Chapter 3) suggests that the higher mortality among the staff did not reduce the ability of the sector to provide health services, as between 1990 and 2000 the number of doctors and nurses at all levels of care typically tripled (table 4.2, Chapter 2) due to the hiring of new staff. Interestingly, however, in Kenya the recruitment of new health staff was seemingly not driven by the desire to combat HIV/AIDS but by the policy to improve geographical access and overall service quality. Yet, even this rapid expansion of health infrastructure was largely surpassed by the additional demand for health services triggered by AIDS. As for Côte d'Ivoire, Pégatiénan and Blibolo (Chapter 5) suggest that the number of doctors, nurses, administrators and beds in primary care increased since 1993, also in this case not to respond to the AIDS pandemic but to expand the reach of PHC. Here too however, the indications are contradictory. Indeed, 87 percent of the stakeholders interviewed indicated that the surge in the demand for AIDS care reduced the availability of services for other diseases. Likewise, Verma et al argue in Chapter 8 that in the Sangli district of India the stakeholders identified the weakness of the rural infrastructure for preventing, diagnosing and treating AIDS and the poor training of the staff (as well as the discrimination of HIV patients) as the main problems of the health sector.

Finally, in China, the problem of public care of HIV has been compounded by the dismantling of the commune-based health care and the de facto privatisation of health

services. With the changes in health financing introduced since 1978, most of the rural population and about half of the urban one are without insurance. Out of pockets payments have increased sharply and increases in user fees correlate with decreased service utilisation. Prenatal care has also declined and so has hospitalisation both because of the excessive cost of health services. Meanwhile, unofficial health providers tend to over prescribe, especially injections, a trend that raises the risk of infection (Chapter 9). This approach to health care financing is likely to hamper the adoption of appropriate screening and therapeutic approaches to HIV/AIDS.

4.2 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 relative affluence, mobility and status in the community. As noted, their HIV positive status affected the quality of education by increasing the incidence and length of the teachers' 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 AIDS deaths on the stock of teachers has been slow to emerge given the time lag between infection and AIDS death and given - at times – the rise in the numbers of new teachers hired. In Côte d'Ivoire, in 1996-7 out of 218 known deaths of primary school teachers 140 were due to AIDS, broadly entailing a tripling of the normal death rate among teachers. But, the impact on the stock of educators remained bearable. The impact of AIDS death is likely to increase in the future, as suggested in Chapter 12 by Coombe who cites World Bank projections for East African countries suggesting an AIDS-induced loss of 1-2 percent in the total number of teachers every year – possibly creating a teachers shortage towards the end of the decade. Similar projections are presented in the case study on South Africa.

But public policy can reverse drastically this emerging gap. In Kenya (Chapter 3), the number of teachers increased between 1990 and 1995 to stagnate between 1995 and 2000 possibly because of increasing number of deaths, retrenchments due to adjustment programs and freeze of new employments (Chapter 3). Uganda offers an even more striking example of the impact of public policy on the stock of educators and enrolment rates. In this country, the deaths among primary school teachers rose from some 650 to 950 between 1995 and 1998 (with half of the increase explained by AIDS), yet the number of teachers in primary education increased from 74.000 to 101.000 and that in secondary education from 13.000 to 16.000. Also in this case, this expansion was due to the government's commitment to the achievement of the goal of Universal Primary Education to the year 2000. On the face of it, this seems to negate the hypothesis that AIDS will severely affect the supply of educational services. Indeed, even the stakeholders interviewed appreciated the measures to hire new teachers and redeploy old ones.

AIDS has however confronted the education sector with new challenges. HIV orphans, for instance, constitute an entire generation of educationally disenfranchised young people who most often the educational system has not been able to integrate. In many cases they dropped out of school and were not retained long enough to graduate. A related problem is that of stigma in school. Communities believe that if

parents have AIDS so must the children and often try to obstruct the admittance to school of children of positive people to schools.

Finally, the managerial and policy development capacity of the educational sector might have been eroded, though the evidence in this regard is partial (see chapter 12). For sure there is a need to put in place practical strategies to deal with HIV AIDS. Yet, in chapter 12 Coombe argues that there is no evidence that attention has been dedicated to this requirement by the concerned governments. She argues also that there is little research on the costs and implications of the changes needed in teachers training colleges to adjust the pre-service and in-service models and the curricula to the new situation. Similar conclusions are arrived by the case study on Côte d'Ivoire whose educational system is heavily affected by HIV/AIDS but whose Ministry of Education has introduced no measures to respond to the new problem. Likewise, in Kenya there is no evidence that the ministry is considering introducing new policy measures to tackle the problems due to absenteeism and low morale among the staff.

4.3 Social Welfare

Ministries of welfare are traditionally little developed in low income countries. And though HIV/AIDS requires an increased supply of social workers, transfer payments and other schemes to support the efforts of communities in this area, 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 the impoverishment and other problems caused by AIDS (see Chapter 6). But in Côte d'Ivoire the welfare ministry is not only very small but its personnel (about 700 social assistants) remains largely under-utilized right when the demand for its services is rising fast. Likewise, in Kenya, until this time, the government has assigned no resources to the care of orphans. Only a small program on poor relief is being implemented with limited funding. This stagnation is all the more worrying in view of the responses provided by the stakeholders about their perceived needs. In Côte d'Ivoire they felt that the main welfare problem was the rise in the number of orphans and poor. In the Sangli district, the stakeholders prioritised the provision of food assistance to families with HIV parents as well as the provision of a minimum pension of 3-4 \$ a month to be paid to the elderly of infected families who were about to loose the source of social support due to AIDS.

5. Community and public policy responses to the problems of children in world with AIDS

5.1 Prevention of HIV infection

So far, prevention has been the main pillar of the response to HIV/AIDS. Its main component are information and education campaigns (IEC), the distribution of condoms, STD control, blood screening programs, voluntary testing and counselling. The impact of these programs is still being evaluated as some of these programs generate inconsistent results, favourable in some cases, not in others. In South Africa, for instance, despite a large number of AIDS awareness programs and information campaign, a non negligible proportion of the population still ignores the basic facts about AIDS mainly because of illiteracy, geographical isolation or misinformation. In Chapter 8 on the Sangli district in Maharashtra, Verma et al show that despite many

awareness rallies, street plays and poster displays, important segments of the population are still unaware of the basics about AIDS. These segments include migrants working in the sugar cane sector and the general public in the rural areas. In Kenya (Chapter 3), despite success in making information and services available to some 90 percent of the population, HIV prevalence remains high because of lack of behavioural change. In Botswana, antenatal survey data and various KAP surveys show that despite high level of awareness of AIDS and basic HIV/AIDS knowledge, there has been no change in sexual behaviour

These findings for Kenya and Botswana confirm the well-known discrepancy between awareness about AIDS and behavioural change. The latter remains broadly unachievable in several countries. Yet, behavioural change was observed in Thailand following the launch in 1989 of the '100 percent condom use program' for males receiving services from commercial sex workers. The case of Uganda is also often cited in this regard. The reasons for her 'success' (in reducing prevalence rates) are however still disputed. Indeed, the story may be more complex in the 'anomalous success of Uganda' where the relation between IEC campaigns, behavioural change and decline in the infection rate is harder to prove. If this is the case, some prudence should be exercised before adopting the Ugandan model as a blueprint for replication.

One of the problems underscored in studies part of this compilation (Côte d'Ivoire, South Africa and Uganda but not Thailand and Senegal is that prevention suffered from several problems. The info campaigns were generally limited to the major urban centres, were of sporadic nature, rarely targeted the young people and ignored the educational sector – despite the fact that schools are a major source of infection. Most of all, it is difficult to assess the impact of information on changes in risk-prone behaviours

Another problem concerns the availability of condom that – though rising – is often still insufficient. For instance Pégatiénan and Blibolo argue that in Côte d'Ivoire the supply of condoms in 2000 ensured – on average – the availability of 4 condoms per year to every sexually active male. Only in some high–risk groups has condom use increased (92 percent among the customers of prostitutes in Abidjan). Also the demand of condoms may be insufficient, as well illustrated by the China HIV/AIDS Socio-Economic Impact Study Team (Chapter 9). Indeed, a multitude of surveys shows that condom use remains very low throughout China, that condoms are seen more useful for birth control purposes than for avoiding HIV transmission and that in some areas condoms are still taboo. As a result, even in the sex industry, condom use is around 30-40 percent, while much lower rates of condom use are observed in casual encounters.

Voluntary testing has also generated mixed results. To start with, in many countries there are no studies about the acceptability and practicability of testing among the general population. Especially in the absence of any perspective to access an ARV therapy – there is reluctance by both patients and doctors, as in Côte d'Ivoire and Zimbabwe, to promote HIV tests, as it is feared that the possible discovery of their HIV positive status might provoke too large a shock in positive patients who become emotionally unstable, worry about the illness, stop eating and sleeping, get depressed and, in extreme cases, commit suicide. As indicated in Chapter 7, for instance, in

Thailand males with HIV had in 1996 a 60 percent higher chance of committing suicide than non affected people.

5.2 Measures against the stigmatisation of HIV positive children

Another major impact is the systematic marginalisation of people affected by HIV/AIDS. Discrimination takes place in every aspect of life, i.e. at the workplace, in school (see above), at the clinics, in community centres, in business and at play, as indicated by Table 4. Discrimination of HIV positive children deprives them of many of their rights including that to inherit the possessions of their dying parents. Stigma clearly works against prevention. In Phuket, for instance, fear of stigma and isolation leads the people not to disclose their status, a fact that may not help reducing the spread of the contagion. In Yunnan and the rest of China stigma is much stronger in urban areas - and even some hospitals in Beijing refuse to admit HIV patients. As elsewhere, the impact of this attitude, is that people with AIDS do not disclose their status and so render much more difficult the work of prevention.

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 Thailand since 1991 campaigns have been introduced to reduce the fear and stigma of the HIV positive people that were until then generally represented as a source of danger in the media. Despite all these efforts the situation has not significantly changed though levels of acceptance of HIV people may have improved in some areas. This is an area where much more needs to be done. The interviews with the stakeholders carried out as part of this research projects identified that of stigma as one of the main new problems brought about by the epidemic. In Côte d'Ivoire (see Chapter 5) the interviews with the households affected by AIDS indicated that stigma (together with rise in the number of orphans) was considered the most pressing problems.

5.3 Prevention of other-to-child-transmission (PMTCT)

Despite its enormous potential for saving the lives of children, the PMTCT is still lagging behind and only very few countries (Thailand is one of them) have already gone beyond the pilot project phase and extended the programme to a significant amount of the eligible mothers and children. As shown by Janjaroen and Khamman in chapter 7, in Thailand the Ministry of Public Health started already in 1993 to provide milk substitutes to children born from a positive mother, while later on AZT started to be distributed for free to pregnant women in two of the country's twelve regions. Over 1998-2000, the program was extended to about half of the country: and 75 percent of the women undergoing antenatal care agreed to be tested and 64 percent of those positive were given short-course AZT. In addition, since 2002, the government has started to provide combination therapy to 500 mothers with HIV, i.e.5 percent of those included in the PMTCT programme. The government of Uganda in cooperation with UNAIDS and UNICEF has launched a similar programme, though by end 2001 only 1600 women (about half of those found positive out 27.000 women tested, who were in turn half of those attending the ANC) were being treated with nevirapine (see Table 3.5 in Chapter 3). A similar gradual UNICEF-assisted programme is underway in Kenya.

In South Africa, in contrast, the program was proposed in 1998 but was considered too expensive and was abandoned. It is likely however that the introduction of nevirapine - that costs about one hundredth of the ATZ based therapy – will provide new incentives for the implementation of the programme. Likewise, in Côte d'Ivoire, there is agreement on the programme, but financial and material difficulties concerning the training of health workers, equipment and screening labs and drug procurement explain the program delay.

5.4 Access to antiretrovirals for adults

Adults access to antiretroviral (ARV) drugs carries a strong potential for improving the well being of children. The therapy improves survival chances substantially and permits to carry on an almost normal life as HIV becomes a chronic but no longer lethal disease. Besides of the intrinsic value of saving lives, ARV therapy would reduce the death rate among adults and the rise in the number of poor, orphans and emotionally deprived children. As shown by Chirac in Chapter 15, however, at moment only a negligible proportion of the infected population has access to the ARV therapy. The few exceptions include Argentina, Brazil and Mexico, i.e. middle income countries with low prevalence and public financing of ARV.

As shown by Janjaroen and Khamman in Chapter 7, in Thailand, the public policy in this area changed over time. Already in 1995, 3.600 people out of about 20.000 people with full blown AIDS were treated for free with ARV. Despite the minimal increase in spending that would have been required for the expansion of the program, if generic drugs had been used, changes in the branded drugs prices and procurement policy, as well as problems of patient compliance, lack of follow up by doctors, limited efficacy of monotherapy and the perception that full coverage of the therapy was unaffordable caused a scaling back of the program. The claim about the excessive cost of the program seems however unrealistic as the total AIDS budget absorbed only a tiny 0.02-0.04 percent of GDP. Hopefully, the decline in the prices of the three-therapy, and its greater efficacy will help assigning this program greater priority than in the recent past.

With these few exceptions, access to ARV is financed by private incomes with the results that the number of patients under therapy generally does not exceed a thousand units per country. In hard hit sub-Saharan Africa, for instance, ARV therapy has yet to begin on any significant scale. Even in the 'successful case' of Uganda (Chapter 2) where government provides affordable drugs for opportunistic infections, ARV drugs are made available only to those who can afford them. By 2000 only 540 people were under treatment. A similar stance was voiced until recently by the Health Minister of South Africa. In Kenya, 6300 patients (5 percent of the target population) have been treated with ARV but many of them received only one of the three drugs required. Most of the drugs are available but at a cost as high as in the industrialized countries, so that many have abandoned the treatment after sometime for sheer lack of money. A bill of law on generic drugs was approved in 2001 and government measures to train health care providers, develop treatment protocols and improve laboratory support are likely to reduce drug prices and the problems posed by the lack of infrastructure.

To improve access to ARVs, some multinational companies have introduced drug donations and price discounts programs. In Côte d'Ivoire (Chapter 5), for instance, the price patients have to pay for ARV dropped from CFAF 300.000 in 1998 to 5.000

CFAF today. Meanwhile governments introduced some financing mechanisms to socialize the costs of ARV drugs, as in the case of the Ivorian Solidarity Fund, and developed procedures for determining the eligibility for treatment of AIDS patients on the basis of their socio-economic and medical conditions (an in Senegal). While useful, these measures have not led to any serious breakthrough in ARV coverage. Thus, the issue of legal access to generic ARV drugs remains central. In this regard, a rapid drop in the price of generic drugs seems now increasingly feasible following the WTO Doha meeting of September 2001 that authorizes countries to produce generics ARV or to issue parallel licences to import generics.

5.4 Orphans' care and social assistance to the poor

This is an area where a lot of experimentation has happened at the local and CBO level, but where at the same time public policy has generally lagged behind. The official position has been to focus on community-based and NGO-based care. Indeed, in situations of temporary crises, communities have shown to be able to provide assistance by relying on informal insurance and assistance mechanisms characterized by limited moral hazard, low information requirements and some redistribution. Such responses work well when the affected families are few but have been unable to protect child wellbeing when AIDS mortality and orphan-hood rates have risen significantly. In addition, as shown by Niang and Van Ufford in Chapter 4, while the families affected by HIV did benefit from the assistance of neighbors, 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 11, 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 as an excuse for their protracted inaction and inability of thinking through the broad-ranging implications of HIV/AIDS. Indeed, in most cases a comprehensive policy on how to tackle the orphans problem and child poverty is simply lacking. The government of Côte d'Ivoire, for instance, responded to the crisis by establishing a number of orphanages and social centres but the number of children these can assist is insignificant in view of the needs (Chapter 5). It also created a body coordinating the NGOs engaged in the fight against AIDS, but none of them deals explicitly with the orphans problem.

Some countries have adopted a more pro-active stance. For instance, South Africa's response to the double scourge of child impoverishment and orphan-hood emphasized reliance on the communities but also the need to provide them with financial support. As illustrated by Desmond and Gow in Chapter 6, this objective was achieved by the establishment and rapid expansion of a means tested 'child support grant' (Rand 110 per month) for poor children, an 'orphan foster grant' (Rand 410 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 program expanded rapidly (from 202.000 children in March 2001 to 758.000 a year later). While coverage is only 18 percent of the eligible population, the grant helps controlling the rise in child poverty due to AIDS. The orphan foster grant, in turn, covers around 50.000 children out of an estimated 250.000 orphans. Its coverage

could be improved by simplifying the application procedure that - at present - requires a court decision to assign a child to a registered foster family (subject to a maximum of 6 children for foster family). The long time needed for processing the applications and the exclusion of informal fosterers hinder the timely provision of support to children.

In Thailand, the provision of income support to the infected and affected children involves public institutions, Buddhist temples, some 500 privately run institutions and 100 NGOs. The Ministry of Welfare provides some nutritional assistance, and half of the affected children receive free milk substitutes and school lunches. The government also provides cash transfers to the elderly, who often raise grandchildren, and suffer from the emotional stress and loss of support due to HIV infection of their adult children. The value of the transfer has risen from 200 Bath/month before to Bath 300 after the crisis and coverage passed from 300.000 to 4000.000. While this rich network of institutions allows to draw on different social resources, this approach suffers from problems of coordination, duplication and exclusion of children in need. The government has increased efforts at coordination, but the situation is not yet satisfactory as there is no mechanisms to ensure that all or most affected children are reached.

Finally, it is worth mentioning that the World Bank increasingly includes some informal transfer mechanism to support local initiatives for the victims of AIDS in the Social Investment Funds and Poverty Reduction Strategy Papers it promotes in various countries. If designed appropriately, such interventions may constitute the embryo of a permanent social security system.

It might be worth concluding noting that while formal systems have many advantages, they need to be adjusted to the administrative, cultural and infrastructural realities of developing countries. The western model of social assistance is in fact characterized by heavy informational requirements an approach that would exclude most eligible people for problems of program design, as in South Africa where grandmothers are unable to qualify for foster grants as their names do not coincide with those of the orphans or where many children do not have a birth certificate.

6. 'Best practice' policy responses

6.1. Policy context

The situation of children in AIDS affected societies illustrated in this study requires responses inspired by a considerable sense of urgency and priority, features that have not characterized so far policy action in most cases. In some instances - as in the case of Kenya, Côte d' Ivoire and Malawi - the major problem is the sheer lack of a HIV/AIDS policy. As mentioned by K'Oyugi and Muita in Chapter 3, for instance, between 1984 and 1989 the Kenyan government did not consider HIV/AIDS a serious problem. And its position changed little over 1992-6. Only in 1999, the parliament declared HIV/AIDS a national disaster and started assigning funds to NAC. In other cases, the overall public response to AIDS 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, education policy for AIDS and others that are completely missing.

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 HIV/AIDS battle on the other. Most AIDS affected countries do not count on effective and capillary bureaucracies connecting in an efficient and inclusive way the central government and the local communities and their organs. In most cases, tradition has it that communities cultivate a centuries old sense of self reliance and central government are happy to play a passive role, justifying this passing of the bucket to the communities on the basis of social traditions and cultural norms which – clearly – are institutionally inadequate in front of the enormity and complexity of the HIV/AIDS challenge. Unfortunately, the institutional gap between central power and local communities is only slowly being filled.

Thirdly, in most cases (as in Côte d'Ivoire) governments still see HIVAIDS as a health problem and are slow in realizing that the social and economic impact of the disease requires broader policy responses and adequate resource allocations. Part of the problem is the understandable tendency to focus only on those infected and not on those affected indirectly by the disease. As noted by Barnett and Whiteside in Chapter 11, an analysis of the Bukoba district of Tanzania showed that while 32 percent of the families had been directly affected by AIDS, another 29 percent had experienced ripple effects due to the obligation in fostering orphans, providing labour or cash to help the sick person and providing for survivors. An element of the new policy response is therefore to target both the people infected as well as affected.

Part of this delay may be due to the fact that such impacts were until recently poorly documented, surveyed and analysed. This response gap is particularly evident – even in success cases as Thailand – in the management of the orphan problems (including in terms of the psychological problems that mass orphan-hood can generate), the treatment of AIDS infected patients with ARV, the weakening of the teaching and of the ministries of health and education services. Also, the systemic if slowly evolving economic and poverty impact of HIV/AIDS – particularly on children – has not yet been given a serious thought though some programs promoted by the World Bank (SIF and PRSP) and UNICEF have recently started to draw the attention of policy makers in this direction

Finally, the legal and human rights implications (loss of inheritance, discrimination at work, and other situations) the legal violation of children, women and the elderly in AIDS affected families. In all these areas, public policy has to set broad policy frameworks, establish institutional arrangements to support the communities and local governments in their fights against AIDS and help securing adequate resources for these activities.

6.2 Health policies

(i) a more targeted and sustained prevention of the spread of HIV. In all countries - with low/high prevalence, rich/poor, able/unable to manufacture ARV, etc. – prevention remains the pillar of the overall health policy. It requires strong

political commitment (as in Uganda and Senegal) and social mobilisation (as in Thailand) and demands – from the beginning – a clear recognition of the HIV/AIDS problem and its impact on society.

Information campaigns aiming at changing risky behaviours need to be institutionalised and sustained over time including in countries that successfully reducing prevalence rates - such as Uganda and Thailand, as a relaxation in prevention could push prevalence rates upwards again. Second, as shown by the experience of Senegal and Thailand, such campaigns have to be more focused on high-risk groups and include rural and remote areas where the present low prevalence is likely to increase because of growing rural urban interaction. And third, such programs need to be redesigned. So far they have mostly taken inspiration from an 'information dissemination model' according to which an increase in knowledge automatically triggers changes in behaviour. New programs must pay much greater attention to the perceived incentives, attitudes and other factors in behavioural change in the groups resilient to prevention messages, such as drugs users and sex workers who make the expansion of the necessary programs much more difficult. The school system ought to play a much bigger role than done so far in this area, so as to reach the youth at a very young age. Such programs may consider also more carefully the skills (e.g. in the field of counselling and life-skills teaching) required for achieving such objectives, as well as for providing services to high risk groups

Best practice policies in prevention require also a strong focus on the capillary treatment of STD. One of the reasons of Senegal's success in prevention in the 1990s was the existence of a policy of legalisation of and STD treatment among the sexworkers since well before the outbreak of HIV

Voluntary testing for HIV has been shown to reduce transmission, but in many cases it is hampered by the patient's fear of the results of the test, that in case of a positive outcome are tantamount to a death sentence, by the doctors attitude that fear to traumatize the patients found to be positive, and by the social stigma that surrounds HIV status. This is an activity which requires supporting efforts in the fields of privacy protection, counselling and palliative care. In the absence of the prospects for treatment, the incentives to test – and therefore to limit the spread of the contagion - are much less.

In all countries – and especially in China - secure blood transfusion and proper screening of blood products as well as appropriate measures in the use of disposable syringes or sterilisation must be introduced such as blood screening and the introduction of mono-use syringes -

(ii) PMTCT. The initial – but very limited - successes recorded in the field of PMTCT need to be consolidated and extended. Of the nine country studies analysed, only Thailand and to a lesser extent Uganda and Kenya have sizeable programs underway. Côte d'Ivoire and South Africa cited financial difficulties and organisational programs preventing the start of the program. The cost of PMTCT is low – even for low-income countries - and its benefits very high both in terms of lower infant and child death rates, a major problem even in countries – such as Thailand – that have reduced HIV prevalence, and in terms of savings on the costs of treating paediatric AIDS cases.

The main problem with the implementation of this program is institutional and managerial, particularly in a context of declining budgets and the limited coverage of the health care infrastructure. For instance, while three-quarters of women receive some antenatal care during pregnancy, less than half have trained staff present during delivery. In addition, implementations of PMTCT requires the establishment and management of voluntary counselling and testing to identify HIV positive women, antenatal interventions, modified midwifery and infant feeding practices, treatment with Nevirapine, free milk substitutes for 6 months and prophylaxis for opportunistic infections

(iii) strengthening PHC as a pillar of the entire health efforts, for both AIDS and non AIDS. The spread of the HIV virus has entailed in many countries the weakening of the PHC system, though others – such as Uganda – have expanded their basic health infrastructure precisely during this period. Chapter 13 shows for instance that immunisation rates and maternal and child health services have deteriorated in several African in line with the spread of HIV/AIDS and the crowding out of non-AIDS health care services.

A top priority is thus to 'shelter' the essential activities that are part of PHC, while at the same time seeking synergies between the treatment of HIV/AIDS and non-HIV/AIDS related ailments, for instance by strengthening those activities, such as the Essential Drugs Program and the District Pharmacies, that play a key role in the fight against both HIV/AIDS and other diseases. In view of their limited development, such programs need to be sustained and, in many cases, expanded. The human and physical infrastructure of the essential drug program would also be crucial for the acquisition, storage, control and expanded coverage of an ARV treatment program.

(iv) safeguarding the overall functioning of the health sector. The strengthening of the entire health care system is also an essential objective as one of the impacts of AIDS is to weaken public and private health institutions by killing nurses and doctors, increasing their turnover, affecting their morale and exposing them to considerable stress and risk of burnout. A first response must be in the field of manpower supply and training. As shown by the case studies on Uganda and Kenya the number of doctors, nurses and other people have steadily expanded during the last ten years. Manpower requirements will be influenced also by decisions in the field of palliative care and the simplification of antiretroviral protocols. Put simply, in some countries there is a need for replacing dying, sick or out-migrating doctors and nurses. Even more, there is a need to train nurses to administer a home-based simplified ARV therapeutic protocol.

A second step concerns the distribution and organisational structure of the health services. Rural health services are rarer than in urban area while regional imbalances causes shortages of personnel in certain areas and impede the extension of PMTCT and ARV therapy that in some cases could rise several times by better using the existing infrastructure. Obviously, the strengthening of the health system will be influenced by its existing coverage and by how well the initial program works.

(v) gradually expanding access to ARV. A gradual expansion of ARV coverage would bring notable benefits to AIDS affected societies and to their children. Lack of

treatment would abandon 40 million infected adults and children to certain death. ARV treatment is also useful to enhance prevention. Thirdly, treatment reduces massively the costs of palliative care and the treatment of opportunistic infections. Fourth, a gradual expansion of ARV treatment would involve the strengthening of the overall health system and pharmaceutical infrastructure thus benefiting also overall health care. Finally, and increasingly so, ARV therapy would reduce the devastating effects of AIDS - observed also in countries such as Thailand that successfully reduced prevalence - in terms of rising AIDS deaths among productive adults, number of orphans, impoverishment of a large section of society, weakening of health and education ministries and growing fragmentation of society.

Some countries (Brazil, Mexico, Thailand over 1995-7) have already experimented the ARV therapy on a sufficiently large scale. Demand for ARV treatment emanates also clearly and strongly from the focus group discussions held as part of the study in several Thai locations (Phayao, Bangkok, Rayong, Phuket). One of the most common complaint of the stakeholders interviewed was that AZT or alternative drugs should be provided for free to every person that has a CD4 count of less than 200.

Chirac in Chapter 14 and Cornia et al in chapter 13 show that the obstacles to treatment with ARV (high cost, complex therapeutic protocols and lack of infrastructure) are being slowly overcome. ARV therapy should thus be extended on a priority basis – as done in Thailand - to mothers of children born with HIV/AIDS and professionals difficult to replace and then to people regardless of their income level, depending on ease of access. To achieve this objective, a number of essential steps are in order. The most urgent is the further lowering of he price of ARV drugs from the present level of 300 \$ per patient/year, by liberalizing the production and parallel imports or generic drugs and increasing competition among generic producers and multinationals, or by having the latter to sell the ARV at their marginal cost of production (plus a fair profit margin) i.e. excluding the cost of research and product development. The declaration on TRIPS at the Doha Conference in November 2001 is an important political step in that direction. Ensuring competition among generic producers and the creation of an international procurement system for AIDS drugs would be two key steps to keep prices low. Drug donations, large discounts and marginal pricing are also useful but are less attractive.

Therapeutic protocols and drug regimens needs also to be simplified. Among the desirable changes in this area, Chirac (see Chapter 14) enumerates the following necessary steps: the adoption of single daily doses facilitates patient's adherence to the therapy; the introduction of clinical (rather than lab-based) monitoring of the disease; structured treatment interruptions, the adoption of the DOT protocol and simplification of the lab tests necessary to detect possible treatment failure. Within this, a key role of governments is to develop treatment guidelines and train and certify the staff overseeing the administration of the therapy. While fully trained medical doctors will continue to diagnose the disease and prescribe the therapy, paraprofessionals could assist physicians with less technical tasks, and in supporting patients compliance.

The gradual scaling up of treatment coverage would permit to reach most AIDS patients in several middle-income countries with moderate HIV prevalence, such as Thailand and several Latin American countries. In low-income, high-prevalence

countries, the situation is less rosy, but assuming the changes discussed above and the mobilisation of some 5 percent o the GDP from national budgets (that still assign to AIDS some 2-3 percent of the total health budgets), through the promotion of health insurance and greater inflows of international resources from institutions such as the Global Fund to fight AIDS, TBC and Malaria. Under these ambitious if feasible conditions about of the AIDS affected population in low-income, high-prevalence countries could be treated by the year 2010.

(vi) Which balance between prevention and ARV therapy? So far, especially in high prevalence countries, policy makers have opted for allocating all their scarce health resources to prevention (and palliative care). The main reason for this (see the 1998 statement of the South African minister of Health in Chapter 6) was the high unit cost of the ARV treatment. The selection of the optimal expenditure mix is obviously conditioned by factors such as the level of the HIV prevalence rate, GNP per capita and distribution, strength of health infrastructure, cost and efficacy of prevention and treatment; coverage of health insurance; and ability to manufacture or import generics antiretrovirals. But it depends also on the choice of policy objective. If this is to 'minimize the HIV prevalence rate' the decision to prioritise prevention is socially optimal. This conclusion may be in part modified, however, if account is taken of the enhancing effects of the ARV treatment on prevention (incentives to undergo voluntary testing and modify sex behaviours while reducing the viral load) and the recent drastic fall of generic and branded ARVs.

The optimal mix of interventions may also change if the objective is to 'maximize the years of life'. As shown, tellingly, by the experience of Thailand a decline in HIV prevalence has been accompanied by a rise in AIDS deaths and in the number of orphans. From this, a broadening of the policy objective. Chapter 13 by Cornia, Patel and Zagonari presents simulations that, under plausible conditions, suggests that prevention would receive over 80 percent of total public health expenditure (and ARV less than 20 percent) in case of the policy objective is to reduce prevalence but only between 33 and 79 percent (depending on the cost of the drugs) if the objective is to maximize the years of life lived. In this case, sizeable changes in the relative price of ARV drugs (that has been falling rapidly) vis-à-vis that of prevention shift visibly the allocative mix if favour of treatment, though the model shows that the all people would still be exposed to preventative messages.

Finally, the benefits of ARV treatment are even more evident if the policy maker took into account also the benefits due to a slower rise in the number of orphans lacking parental guidance; the lower demand for various AIDS related orphan allowances and other social security payments; the savings on palliative care and opportunistic infections; the slow down in economic growth (estimated at 0.5 to 1.0 per year in most countries with medium high prevalence). While the numerical examples and arguments given above provide only broad orders of magnitude, they suggest a more nuanced policy stance in relation to the traditional position focussing on prevention only.

6.2 Education

HIV/AIDS represents the largest single threat to education. Schools are a high-risk environment. For instance, one third of the HIV positive people in South Africa were

infected during their school years. The high infection rate among teachers — one important contributor to the spread of the disease - makes these very efficient propagators of the disease and a major source of infection. Yet, as argued by Coombe in Chapter 12, schools can do much to promote the fight against AIDS. To start with, the educational system should become a far more important instrument of prevention especially for the young ones. This requires substantially increased awareness of and knowledge about HIV/AIDS among the educators. Preservice and inservice programs for teachers need to be adjusted so as to provide training on AIDS aetiology, sex education, counselling techniques, ARV therapy and so on.

The teachers will need also to learn how to respond to some of the emerging educational problems of the AIDS era, be they how to teach an increasing number of traumatized and HIV positive and orphans children, how to provide subsides for orphans (as in Botswana) to keep children in school. Teachers ought also to take a more active role in sex education and life skills. Stakeholders in Sangli district of India consider that health and sex education should be carried out in schools, while school fees should be waived for infected and affected families

A second area of intervention concerns youth awareness of HIV/AIDS. Considerable curriculum adjustment is necessary in this regard. In many communities belief persists that any kind of sexual education leads to increased sexual activity, though studies in Africa show that young people that participate in sexual education do not become more promiscuous. Sex education should go hand in hand with the respect of women and girls who have often been the victims of rape and contagion. This means among other things, creating acceptably healthy and secure and compassionate learning environments with separate dorms and toilets.

A third policy that needs to be introduced more broadly concerns the universal waiver of primary school fees (as already done in Malawi, Tanzania, Uganda) and introduction of school feeding programmes. Careful design of selective fee waiver programs ought to avoid the stigma that such programs generate.

Best practice policies should avoid also the collapse of the educational system due to a rapid decline in the number of educators and administrative chaos because of the death of key administrators. Attention to the need for accelerated teachers and managers training is also an essential best practice policy. Though there is no evidence that massive AIDS deaths have – yet – crippled the supply of educational services, it has been argued that this problem may arise in the years ahead in those countries which have experienced high HIV prevalence already for years. The educational planners should therefore consider this eventuality with adequate anticipation. A related – even more urgent – problem is how to offset the perceptible decline in education quality due to increased absenteeism, sickness and low morale among teachers, with the extension of ARV therapy and counselling among sick teachers being one of the options and the hiring of 'barefoot teachers' and - multi grade teaching, in remote areas. A related issue concerns the improved management of the system.

6.3 Orphans and abandoned children.

A critical challenge in this area concerns the identification of what is 'best practice' as there are several approaches being experimented with success under different local circumstances. Also, what works well locally, may not work as well when replicated on a wider scale.

Some of the problems in introducing 'best practice' interventions or in expanding their scale are technical, but other are grounded in the political economy of the response, as governments may be reluctant to promote them if these implicitly criticize their past approaches or lack of action in this area. In countries with mature epidemics such as Kenya and Côte d'Ivoire, for instance, the government has not developed any 'orphan policy'. And in countries, such as China and India, local authorities and central governments are only now starting to think about what may turn into a serious orphans crisis in a decade. Even in Thailand, where – because of the timid approach to ARV therapy – the number of orphans is expected to triple over the next several years. Even in this country, the orphans strategy, the financial support it requires, the efforts needed to deal with the emotional deficit of orphans and so on are still to be fully worked out. Be as it may, in Chapter 15 Phiri and Webb identify the following alternative to orphan care:

- institutional care in state or religious orphanages is seldom the preferred option, except in case of children severely abused or requiring highly specialized assistance. Large orphanages tends to be big in size but rare. They are often seen as appealing by the relatives of the poor children because of the perception that they are well funded and can thus solve the material needs of children. Several studies show that the majority of children were interned in orphanages not so much for the death of a parent but because of poverty or divorce. These institutions however suffer from well-known problems: first of all, their unit costs are high (between 600 and 2.000 US\$ per child/year) so that it is impossible to replicate such 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-type environment offers: the contacts between children, the adult role models and society at large are limited and socialisation occurs mainly among peers. As a result, children in institutions lack basic social, cultural and parental skills, have relational difficulties and find difficult to adjust to the external environment once leaving the orphanage. And third, the children in orphanages have tenuous ties with the clans and villages from which they originate. This lack of connectedness is particularly important in Asia and Africa and is an important component of the personal identity of the child.
- local-level 'informal fostering' based on blood ties, religiosity, informal solidarity or reciprocal insurance and social assistance contracts. This approach is dominant in many traditional societies of Africa and Asia but may not be easily scaled up and needs, in any case, to be accompanied by some collective action to ensure that it counts on adequate resources and that it is submitted to some external monitoring. But it might be difficult to support families with AIDS orphans. Targeting is complicated and may not be desirable because it could be stigmatising. Botswana has provided funding but has not yet developed the institutional structures to support, monitor and supplement the traditional work of foster families, communities, churches and NGOs

in this area. Institutional development takes time and should be dealt on a priority basis

- community based registered and often unregistered <u>'children's homes and orphanages</u>' have increasingly absorbed a huge number of orphans even if little is known about this. Phiri and Webb, for instance, mention that the number of HIV positive children (not necessarily orphans) placed in institutions has increased tenfold in Thailand over the last decade.
- community-based foster families where 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. UWESO) a child support or foster grant for each child as well as a small allowance for herself (see Chapter 6). At times, the transfers of foster grants by state institutions faces administrative and eligibility problem as, in the case of South Africa where abandoned children may lack ID 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 per primary school and 75\$ for secondary), health costs and clothing. When these resources are scarce, the communities prioritise the neediest children.

The limited evaluations available tend to show that institutional care is the most expensive and less appropriate solution of the orphans problem, and that formal or informal community-based foster care are most effective both in terms of cost efficiency, replicability and closing of the affection gap of orphans. Yet, these local fostering models often do not meet even minimum standards in terms of resource adequacy, child supervision and stimulation and so on. 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 the NGOs. The pros and cons of state transfer payments for orphans have been reviewed above and in section 5.4. How about the NGO sector? What are the 'best practices' so far, and what particular role can they fulfil in low-income societies with weak bureaucracies?

One of the external supports required is that of 'visiting informal 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 who works in close contact with community leaders. All orphans in a given area (regardless of their family arrangements) are enumerated by this NGO (see chapter 15). In addition, trained volunteers (widows or women already caring for orphans) visits them at least twice a month, provide them resources and emotional support and follow the evolution of their material and psychosocial situation of the child. The visiting volunteers make sure that the typical problems affecting orphans (school abandonment, ill health, isolation, 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 in offering 'overall intersectoral assistance' to communities caring for large numbers of orphans. Malawi's COPE, for instance, tries to catalyse the community energies in four areas orphans, youth, prevention, home based care. Its work focuses on the identification, monitoring and protection of orphans through programs such as direct transfers to vulnerable and transient poor, school fee assistance, training, income generating programs and other forms of multisectoral assistance chosen by the communities. At the moment, COPE covers 12 percent of districts of Malawi and aims at covering the whole country by 2006

A specific external resource required by 'best practice' approaches concerns the psychosocial counselling required by the victims of the epidemic. The psychosocial needs of orphans and AIDS affected children are often neglected. AIDS causes not only death, hunger and other material deprivations among orphans but also a sense of abandonment, depression and rejection. Children do not verbalize their feeling, become withdrawn, play truant, antisocial ad may become prone to depression in adult life. Bigger children may enter into conflict with the 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 disease will be rife.

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

6.4. Economic support and welfare transfers to impoverished families (see also 5.3)

(i) economic support. How to fight the long term depressive effect of HIV/AIDS on the economy, and the subsequent impact on higher HIV contagion, reduced access to health care and child poverty? To answer this question, it is necessary to recall that AIDS generates an imperceptible but deepening shock that gradually erodes the stocks of skilled and unskilled labor, land fertility, financial savings, investments and social capital. Accordingly, a policy aiming at sustaining economic growth and avoiding poverty in the AIDS era should prevent the decline of these productive resources or accelerate their creation in those cases AIDS destroys them. This entails not only a capillary work of school-, health- and firm-based work of prevention as discussed in chapters 12 and 13, but also treatment with antiretrovirals for, at least, those workers whose replacement cost is higher than the cost of generic antiretrovirals.

In all cases where the treatment of the workers is impossible, there is a need to accelerate the training of potentially scarce workers. Thus, 'best practice' policy requires to provide budgetary support to the accelerate the training (or importation) of specialized workers, teachers, health professionals and laborers whose shortage could generate a large negative impact, as in the case of people running power grids, water and railway systems, health and education and so on. Targeted interventions in these

sectors can avoid slowdowns in growth. At the community and firm level, one can focus on facilitating the mobility of labor and flexible specialisation. There is already scattered evidence that communities affected by the virus adopt less rigid forms of division of labor by skill level, age and gender and encourage labor pooling arrangements, especially in agriculture.

(ii) Overall anti-poverty measures. In Chapter 10, Cornia and Zagonari argue that HIV/AIDS impoverishes non only the person infected but also – through demand, supply and other systemic effects – also those connected to her by relations of family, employment, trade and exchange. One way to fight these effects is to introduce employment based programs that have the purpose of sustaining the employment and incomes of the families affected while avoiding a deterioration of the community infrastructure. Interviews with HIV/AIDS stakeholders in (Phayao, Thailand), for instance, clearly show that more jobs were required for AIDS patients. There is already considerable experience with the design and management of such programs as suggested by the successful experience of India and Botswana's Labour-Based Relief Programme. The need now is to adjust the design of these programs to the situation of HIV/AIDS affected communities.

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

Broad family-focused income transfers will be necessary for those affected families that cannot be helped through employment based, microcredit and training programs. Besides the targeted child and orphan allowances discussed in section 5.4, 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 immiserisation, sickness, disability and widowhood. The Kerala and Tamil Nadu non-contributory old age pension schemes, for instance, are two good examples of such programs (see chapter 10). The design of such transfer programs is essential for their success, particularly as it concerns the value of the benefit (in Phuket, the PLWA interviewed mentioned that the 'intrusion cost' borne was too high in relation to the smallness of the transfer received), the administrative arrangements adopted for the transfer of the funds and the selection of the eligible families, and accountability. 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 15) suggest, it might be best to rely on federations of accountable umbrella organisations working with children, such as multilayer committee structures, National Funds and faithbased organisations.

7. The political economy of the fight against AIDS

One of the main reasons for the limited success in the fight against AIDS is to be found in the limited commitment of most governments to fight the spread of the disease and to mitigate its impact. Most HIV/AIDS affected countries have been accused of lacking political will and commitment to fight AIDS. However, as it is well known, this has not always been the case and countries such as Senegal, Thailand and, to some extent, Uganda were able to control the adult prevalence rate 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 negated, ignored, removed or trivialized? And, why have some countries allocated substantial resources to its control and mitigation of its long term effects while in others the burden of responding to AIDS has been shifted to the 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 response pivot around the presence or absence of some charismatic leaders (like Museweni in Uganda). But, these explanations are not very convincing.

A first observation is that governments mostly act in response to their perceived self-interest. The first possible explanation of inaction when dealing with AIDS is that the elites ignore or, rather, have only vague information on the nature of the disease, on its spread and impact on the various social groups and on the fact that entire social system may collapse because of it. In this explanation inaction depends on ignorance of the facts. Also, once information on the disease has been received there will be some lags before a response takes shape.

A second explanation is that the political élites is informed about the epidemic but that the situation is so overwhelmingly negative to push the leaders to denial and inaction. In countries like Zambia, for instance, the policy maker confronts a situation by which half of the children born this year will not reach twenty years of age. A third explanation of inaction could come from the fact that the political leadership is fully informed but has no interest to intervene as the group affected belong to racial or social minorities which are not worth investing into, as in the case of Yunnan where in 1990 the HIV/AIDS epidemics affected mostly ethnic minorities of drug users portrayed negatively in the media. In other cases, the disease may affect mainly ethnic or social groups in conflict with the leadership. In South Africa, for instance, the epidemic has for long been far more intense in KwaZulu Natal, whose Inkata party has posed for long a strong (and at times violent) challenge to the central government. This model ('they, not us') is well tested and can explain why the élites do not intervene in favour of different classes, unless they feel they might be affected themselves sooner or later by the same problem.

A fourth possible cause of weak and untimely interventions by governments is that those that should intervene have an incentive in preserving the status quo. In China, for instance, the local bureaucracy generally underplays the extent of the epidemic as it fears it might be sanctioned by the central authority owing for past incompetence or laxity (for instance for its inability in curbing the sale of plasma product to speculators). Indeed, especially in the early stages of the infection, many local

governments, do not want to know about HIV/AIDS and —even more — do not want others to know for fear it will reflect negatively on their locality or on its officials. Also, when the interventions against AIDS requires some control on prostitution, the local authorities that have to enforce the new norms (e.g. the police) retards the intervention as it would loose income by closing the brothels it controls.

Fifth, democracy and a free press should in principle facilitate action against AIDS (as well as famine) as suggested by Amartya Sen. Thailand and Senegal are certainly more democratic countries than several of the high prevalence countries of Eastern and Southern Africa. The democratic process allows the citizens – including those affected by AIDS – to pressurize the governments to act swiftly against the disease. In Senegal, for instance, the parliamentarians were expected to work for the campaign against HIV during the state budget. Also in democratic Thailand, AIDS was soon perceived as a major social problem by the establishment. From this the creation in 1991 of the National Aids Commission, a policy making body chaired by the Prime Minister that has overseen a multisectoral anti-AIDS policy. In contrast, lack of effective democracy and limited involvement by civil society and affected communities in the decision making process contribute to explain the limited political commitment by the Chinese leadership and its hesitant policy response to AIDS. With low – but rapidly rising – infection rates, the authorities are still reluctant to give clear warning messages to the population.

A committed and competent bureaucracy and cohesive civil society are essential for the success of any collective undertaking. Symmetrically, a weak bureaucracy and fragmented civil society are a recipe for stagnation. For instance, the chaotic situation with STD control, the dismantling of public health services, the slow communication between central, local and village authorities represent and the many contradictions between provincial norms and the national guidelines on treatment issued by MOH certainly pose a major obstacle to the fight against AIDS in China. In contrast, the positive interaction between civil society and bureaucracy in Thailand permitted to draw into the fight against AIDS also the private sector, the NGOs and the local communities.

Religious groups — who maintain a strong influence in traditional societies - seem to have plaid a key role in the fight against AIDS. In the early days, in both Kenya and Côte d'Ivoire, religious leaders systematically opposed any effort at AIDS control. In Kenya for instance, until the mid-late 1990s religious organisations opposed the introduction of sex education in schools. At the moment, however, in both countries pastors, priests and imams participate actively to most local levels initiatives in this area. And in Kenya the head of the AIDS commission is now a Protestant or Catholic bishop. In contrast, in Uganda, Thailand and Senegal, the religious authorities always supported — or at least did not engage in any religion war against — the fight against AIDS.