AIDS, PUBLIC POLICY AND CHILD WELL-BEING

edited by
Giovanni Andrea Cornia
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UNICEF Innocenti Research Centre
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(Electronic versions of this publication can be downloaded from the Innocenti website)

Layout & phototypesetting: Bernard & Co, Siena, Italy
Front cover picture: Chris Sattlberger/Panos Pictures
Second edition, available on the Innocenti website
Electronic edition published 2003
ISBN: 978-88-89129-52-4

Currency sums quoted in dollars ($) are United States dollars unless otherwise stated. Exchange rates shown below are United Nations rates per $1.00 averaged over the period March 2003 to March 2006:
China: Renminbi 8.22
Senegal: CFA Franc 543.00
South Africa: Rand 6.63
Thailand: Baht 40.41
Uganda: Ugandan shilling 1,826.00
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ACRONYMS

ACP  AIDS Control Programme (Uganda)
AfriCASO  African Council of AIDS Service Organizations
AIDS  Acquired immunodeficiency syndrome
AIC  AIDS Information Centre (Uganda)
ART  Antiretroviral therapy
ARV  Antiretroviral
ASSA  Actuarial Society of South Africa
AZT  Azidothymidine (zidovudine)
BIDPA  Botswana Institute for Development Policy Analysis
CBO  Community-based organization
CDC  Centers for Disease Control and Prevention (United States)
CFA  Communauté Financière d’Afrique (West African francs)
CGE  Computable general equilibrium (models)
CINDI  Children in Distress (South Africa)
CMR  Child mortality rate (under-five-deaths per 1,000 live births)
COPE  Community-Based Options for Protection and Empowerment (Malawi)
CRC  Convention on the Rights of the Child (United Nations)
DFID  Department for International Development (United Kingdom)
DOT  Directly observed therapy (of tuberculosis)
DPT  Diphtheria, pertussis and tetanus (immunization)
ECA  Economic Commission for Africa (United Nations)
ECOWAS  Economic Community of West African States
EFA  Education for All
FAO  Food and Agriculture Organization of the United Nations
FBO  Faith-based organization
FCE  Final household consumption expenditure
FGM/C  Female genital mutilation/cutting
FXB  Association François-Xavier Bagnoud
FY  Fiscal year
GDP  Gross domestic product
GNP  Gross national product
HAART  Highly active antiretroviral therapy
HE  Health educator
HIPC  Heavily Indebted Poor Countries initiative
HIV  Human immunodeficiency virus
IAVI  International AIDS Vaccine Initiative
IDPs  Internally displaced persons
IDU  Injecting drug users
IEC  Information, education and communication
IFAD  International Fund for Agricultural Development
IEP  International Institute for Educational Planning
ILO  International Labour Organization
IMR  Infant mortality rate (under-one-deaths per 1,000 live births)
KABP  Knowledge, attitude, behaviour and practice (surveys)
MAP  Multi-Country AIDS Programme for Africa (World Bank)
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>MMR</td>
<td>Maternal mortality ratio</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
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<tr>
<td>MoPH</td>
<td>Ministry of Public Health</td>
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<tr>
<td>MSF</td>
<td>Médecins Sans Frontières</td>
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<tr>
<td>MTCT</td>
<td>Mother-to-child transmission (of HIV)</td>
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<tr>
<td>NAC</td>
<td>National AIDS Prevention and Control Committee (Thailand)</td>
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<td>NCC</td>
<td>National Council for Children (Uganda)</td>
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<tr>
<td>NGO</td>
<td>Non-governmental organization</td>
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<tr>
<td>NIP</td>
<td>National Integrated Plan (South Africa)</td>
</tr>
<tr>
<td>OAU</td>
<td>Organization of African Unity (replaced by the African Union)</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation for Economic Co-operation and Development</td>
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<tr>
<td>OMS</td>
<td>Organization mondiale de la santé (World Health Organization)</td>
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<tr>
<td>ONU</td>
<td>Organization des nations unies</td>
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<tr>
<td>ONUSIDA</td>
<td>Programme commun des Nations Unies sur le VIH/SIDA (UNAIDS)</td>
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<tr>
<td>ORT</td>
<td>Oral rehydration therapy</td>
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<tr>
<td>OVC</td>
<td>Orphans and vulnerable children</td>
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<tr>
<td>PEARL</td>
<td>Programme for Enhancing Adolescent Reproductive Life (Uganda)</td>
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<tr>
<td>PEPFAR</td>
<td>United States President’s Emergency Plan for AIDS Relief</td>
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<td>PHC</td>
<td>Primary health care</td>
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<td>PLHIV</td>
<td>People living with HIV</td>
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<td>PLWHA</td>
<td>People living with HIV and AIDS</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of mother-to-child transmission (of HIV)</td>
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<td>PRSP</td>
<td>Poverty reduction strategy papers</td>
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<td>PWA</td>
<td>People with AIDS</td>
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<td>SADC</td>
<td>Southern African Development Community</td>
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<td>SCF</td>
<td>Save the Children Fund</td>
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<td>SIF</td>
<td>Social investment fund (World Bank)</td>
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<td>STD</td>
<td>Sexually transmitted diseases</td>
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<td>STI</td>
<td>Sexually transmitted infections</td>
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<td>SW</td>
<td>Sex worker</td>
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<td>TASO</td>
<td>The AIDS Support Organization (Uganda)</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<td>U5MR</td>
<td>Under-five mortality rate (per 1,000 live births)</td>
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<td>UAC</td>
<td>Uganda AIDS Commission</td>
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<td>UBC-HIV/AIDS</td>
<td>Uganda Business Coalition on HIV/AIDS</td>
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<td>UCOBAC</td>
<td>Uganda Community-Based Association for Child Welfare</td>
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<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<td>UNASO</td>
<td>Uganda Network of AIDS Service Organisations</td>
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<td>UNDP</td>
<td>United Nations Development Programme</td>
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<td>UNESCO</td>
<td>United Nations Educational, Scientific and Cultural Organization</td>
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<td>UNFPA</td>
<td>United Nations Population Fund</td>
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<tr>
<td>UPE</td>
<td>Universal primary education</td>
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<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
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<td>UVRI</td>
<td>Uganda Virus Research Institute</td>
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<td>UWESO</td>
<td>Uganda Women’s Effort to Save Orphans</td>
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<td>VCT</td>
<td>Voluntary counselling and testing</td>
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Introduction and Acknowledgements

This study addresses one of the greatest challenges of our time: the damage caused by HIV and AIDS to the well-being of children and families. With 38.6 million people affected by HIV in 2006, with HIV prevalence at antenatal clinics exceeding 40 per cent in areas of Botswana and KwaZulu-Natal (South Africa), with nationwide adult prevalence in excess of the critical threshold of 20 per cent in several countries, and with the prospect of a rapid spread of the disease in large swathes of India, China and Russian Federation, the future of child well-being is seriously threatened. Certainly, in the 50 or so countries affected by the disease, the Millennium Development Goals in the field of child survival, education, poverty and basic rights will be missed, often by a large margin.

While the challenge posed by HIV to health has been universally recognized, in most countries, the specific impact of HIV on children remains – with the exception of the orphans problem – poorly documented, analysed, understood and responded to. Indeed, most of the debate on the impact of HIV has focused on adult prevalence and death rates, on ways to control the spread of the disease over the short term, and on increasing the availability of antiretroviral drugs. While understandable, this approach has diverted the attention of the national authorities and international agencies from the recent deterioration in infant and child mortality, enrolment rates, nutritional status and emotional development that has taken place in several countries, from the many pernicious ways through which HIV affects child well-being, and from the urgent need to strengthen traditional interventions and to introduce new ones to address the impact of HIV on children’s lives.

Even when recent studies and programme responses have focused specifically on children, they have concentrated mainly on the children of families directly affected by AIDS. However, as this study shows, the impact of AIDS is far broader. The disease devastates the entire society – economy, demography and social relations – and its effects are felt by the vast majority of the children, whether from HIV-affected families or not.

Another gap in the AIDS policy debate and practice concerns the measures needed to mitigate the impact of the epidemic on children, all children. So far, the response has been dominated by measures to control HIV prevalence through information campaigns, the palliative care of HIV-positive adults, and support to the care of orphans. Until recent years, budgetary support and international aid to these activities have been limited, thus leaving the communities alone in ‘coping’ with a daunting task. In all these cases, broader insurance and redistributive policies, including income transfers, are needed. Public policy must – in addition – broaden its scope as, even in countries such as Thailand that recorded a reduction in prevalence, we have witnessed a rapid rise in cases of paediatric AIDS, mortality among adults and the number of orphans. Public policy ought therefore to play a more
proactive and longer-term role than it has done so far, by strengthening primary health care as the main vehicle for the treatment of all child diseases, by a further expansion of prevention of mother-to-child transmission of HIV programmes, by accelerating the treatment of mothers and other adults with generic antiretrovirals, by stepping up the formation of teachers, doctors, technical staff and administrators to prevent the collapse of public services and the economy, by waiving user fees in the social sector, and providing stronger budgetary support and international aid in favour of AIDS programmes. Government support to families with orphans, foster families, nutritional programmes relief for the poor and so on, affecting both HIV-affected and non-affected but impoverished populations, has also to be strengthened, both financially and institutionally.

To help focus the attention of policymakers, communities, practitioners and scholars on the impact of HIV on children, in late 2000, the Florence-based UNICEF Innocenti Research Centre sponsored, with the support of UNICEF’s New York Headquarters and its Regional Office for Eastern and Southern Africa, a global study in this field. The study was initially based on nine country case studies (six in Africa and three in Asia) and a review of the impact of HIV and AIDS in six key areas, namely, the health sector, the education sector, access to antiretrovirals, economic impact, child impoverishment and orphanhood. Participants in the project initially met in Nairobi to discuss the research scope, methodology and surveying needs of the study. They subsequently reconvened in Florence in the Spring of 2002 to review the first complete drafts of the contributions included in the study. The first version of the study was placed on IRC’s website in 2003.

In 2005, it was felt that the further diffusion of the research required the production of an updated book version of the study. The original work was therefore updated and re-edited. Maryam Farzanegan and David Parker of UNICEF IRC managed the production of this revised and updated study, which was patiently and efficiently edited by Vicky Haeri in collaboration with the chapter authors. In this process, however, three case studies (Côte d’Ivoire, India and Kenya) as well as the sectoral chapter on antiretrovirals had to be dropped as their authors had moved to other occupations and could not work on their revision.

This volume would not have been produced without the support and collective effort of many other people working together in myriad ways. To start with, my sincere thanks go to Mehr Khan, Director of UNICEF IRC when this research project was initiated, for enthusiastically accepting my proposal to launch a study in this area. My gratitude goes also to Urban Jonsson, former UNICEF Regional Director for Eastern and Southern Africa, and Mark Sterling, then the AIDS group coordinator in UNICEF Headquarters, for the strong support, research insights and partial financing they provided to the project. Warm thanks also go to the contributors for their precious time and scholarly application, their original analyses and
their patience in revising their papers. At UNICEF IRC, Sandra Fanfani and Cinzia Iusco Bruschi provided efficient support in administering the project and organizing the Nairobi and Florence meetings, Patrizia Faustini placed the study on the Internet, and Leonardo Menchini provided excellent research assistance.

It is hoped that the rich statistical material, critical analyses and policy and programme proposals presented in the study will help national authorities, practitioners, NGOs, communities and – most of all – the children and families affected by HIV and AIDS in their difficult efforts against this terrible disease. As such, I strongly recommend this study to all those interested in responding to this devastating and historically unprecedented scourge.

Giovanni Andrea Cornia
University of Florence
September 2006
Chapter 1
Overview of the Impact and Best Practice Responses in Favour of Children in a World Affected by HIV and AIDS
Giovanni Andrea Cornia

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

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

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

Context and focus

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

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

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

• For the children of the families affected, the impact of HIV is, without exception, consistently and clearly devastating. But at the macro level, i.e. at the level of national averages for child well-being indicators, the impact only starts to be perceptible when the prevalence exceeds 3–4 per cent. In countries with prevalence around 2–3 per cent (such as Benin, Ghana, Mali and Thailand), the IMR and U5MR continued to decline on trend during the 1990s. In contrast, in about 15 of the 40 countries analysed, the impact of HIV has been very pronounced.
Even when a country does succeed in controlling HIV prevalence, it might not be equally successful in reducing the numbers of those dying or being orphaned due to AIDS, or in combating child poverty and supporting the care, socialization and emotional development of orphans and abandoned children.

While deterioration at the macro level may be evident, the sectoral effects are not necessarily uniform or felt at the same time. The first measurable impacts are likely to be on the quality of education, infant and child mortality rates, and perhaps child nutrition (though evidence in this field is limited). Rises in teachers’ absenteeism, and declines in contact time and morale, are also rapid. Services for non-HIV-infected patients in public hospitals also frequently deteriorate quickly. However, increases in the numbers of children orphaned by AIDS, or collapse of the education system due to school staff dying of AIDS, or the overall impoverishment of families and children because of reduced economic growth, are likely to be felt much later after the initial onset of the epidemic. This is because such impacts occur as the result of the deaths of a large number of parents, teachers and workers, and HIV-positive adults often live for several years after contracting the virus. And some long-term effects – such as those related to the emotional deprivation and mental health of orphans growing up in difficult social arrangements – are only now starting to be perceived.

In several low – and high – prevalence countries, much of the impact of HIV on children still lies ahead. This is clearly the case in high-prevalence South Africa – where the rate is expected to peak around the middle of the decade – as well as in China and India. Although the epidemic is still at an early stage, with 5.1 million HIV-positive people, India has the largest number of people living with HIV outside South Africa (UNAIDS 2005). In China, the number of HIV-positive people has risen exponentially since 1993 in parallel with the increase in sexually transmitted infections. At the end of 2001, it was estimated that 660,000 people were infected. By the end of 2003, the total had reached 840,000 and the national adult prevalence was estimated at around 0.1 per cent (UNAIDS 2004). In the absence of timely and decisive interventions, the epidemic could spread rapidly. The experience of countries such as Senegal and Thailand could provide valuable examples of prevention and mitigation.

Social epidemiology of the disease

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

i) Bio-medical factors include the prevalence of sexually transmitted infections (STIs), poor health and nutritional status, male circumcision and sexual behaviour. STI levels have a major impact on the risk of contracting HIV, but STIs often go
untreated because they tend to be asymptomatic. Data from Kenya show that people with STIs were found to be up to four times more likely to contract HIV than those without. Male circumcision also reduces the risk of contagion (K’Oyugi and Muita 2002).

- In China the **over-use of curative injections** (and tattooing) is another source of infection. It is estimated that children under five are given an average of six injections per year (chapter 6), a fact that certainly contributes to the spread of hepatitis B and to the transmission of HIV. About half the curative injections in China are unsafe because of improper sterilization practices.

- In parts of China, the **sale of blood** is a common survival strategy adopted by the poor. Many sell their blood several times a month for a fee of $5. Blood from people with the same type is pooled and centrifuged to separate the plasma, which is then sold. The remainder of the pooled blood is re-injected into the farmers. As a result, some 1 million people were infected in Henan province alone. In extreme cases, as in blood donor villages in Hebei and Hubei, up to 75 per cent of the people selling their blood tested positive. An October 1998 law banned the sale of blood, but chronic blood shortages, money incentives for the poor and lack of information about HIV make it difficult to eliminate this phenomenon.

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

Domestic **migration** leads to rapid urbanization, which is often associated with the spread of STIs and HIV because of the loosening of social norms regulating premarital sex, lack of sanctions against promiscuity and numerous opportunities to make contacts within a setting of anonymity and low social control. In China, the spread of HIV has probably been facilitated by the massive internal migrations that have involved a ‘floating population’ of over 100 million people. Local surveys from Shanxi show that, of the people who had been found to be positive, two thirds were migrant workers (chapter 6).
• **Location**: HIV prevalence is generally higher in urban than rural areas. Yet, there is evidence that the urban–rural ratio may be reversed over time as prevalence may fall in urban areas because of raised awareness, while the rate in rural areas may catch up. This can happen, for instance, if rural areas provide seasonal manpower to urban areas.

• The incidence of HIV also varies with **social status**. Jobs that give social status and power – as is the case with army personnel (Cambodia, Thailand and Yunnan Province, China) and wealthy managers – exhibit higher rates of infection than the average for males (but not for women). Teachers and health workers enjoy social status and are likely to live away from their families. This exposes them to a greater risk of engaging in sex with multiple partners.

• **Income level and distribution**, poverty, unemployment and marginalization raise the risk of contagion in urban areas. Poverty and uncertainty about the future can lead to short-term survival strategies with risky behaviour. Unemployment and social exclusion are key factors in drug addiction and the risk of infection through intravenous drug use. Income inequality also tends to affect the cohesion of local communities and to reduce their cooperative behaviour.

• **The empowerment of women**, in terms of employment, income and social roles, tends to reduce the risk of contagion. Reducing discrimination against women in these areas increases their independence and ability to negotiate sexual contacts on their own terms. This particularly benefits young girls, who because of existing social norms often get infected at a much younger age than men. A study from South Africa shows that an increase in the income and status of a man tends to increase his risk of infection while the opposite is true for women. A redistribution of income among genders and social classes would therefore reduce HIV incidence. Cross-sectional evidence from Kenya (K’Oyugi and Muita 2002) seems to confirm this finding.

• **Education level**. In the first stage of the HIV pandemic, educated men were particularly hit by HIV as their status allowed them to engage in multiple sexual relationships, effectively exposing them to greater risks of contagion. With the spread of information on prevention, incidence rates in this group have fallen, and most of the burden of the epidemic has shifted to people with lower levels of education and less ability to absorb messages about prevention.

**iii) Cultural norms. Cultural and religious beliefs and practices**, such as attitudes towards early, premarital and extramarital sex, marriage, prostitution, sexual education, condom use, polygamy and wife-sharing, blood brotherhood, widow inheritance and so on, affect the risk of HIV infection. Beliefs about specific sexual practices, such as the supposed curative effects of intercourse with young virgins and the obligation of cleansing sexual practices with widows of deceased
family members, are localized examples of norms contributing to the spread of the disease. K’Oyugi and Muita’s data from Kenya show that women’s risk of becoming HIV-positive varies with their marital status. It is significantly higher among those in polygamous, rather than monogamous, marriages. And it is three times as high among widows (K’Oyugi and Muita 2002).

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

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

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

**Changes in infant and child mortality during the 1990s**

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

In several countries, the unfavourable trend in U5MR will continue in the years
ahead. In South Africa it has been estimated that the rate will rise from 95 to 110 per thousand between 2001 and 2006. In KwaZulu-Natal, the most affected province, it is expected to exceed 140 per thousand in 2006, more than double the rate for 1992 (chapter 4).

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

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

<table>
<thead>
<tr>
<th>Table 1. Percentage of children unable to attend a clinic during the survey period by type of family, 2001</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AIDS death</strong></td>
</tr>
<tr>
<td>Sangli, Maharashtra (India)</td>
</tr>
<tr>
<td>Ugunja, Kenya</td>
</tr>
<tr>
<td>Côte d’Ivoire</td>
</tr>
</tbody>
</table>

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

Third, mortality among children may also rise because of the HIV-induced impoverishment of the family in which the child lives. As discussed in chapter 7, the average income of families whose head had died of an HIV-related illness during the prior 18 months dropped by up to 50 per cent.
Increased mortality due to paediatric AIDS: In 1999 alone, 570,000 infants became infected with HIV worldwide, bringing their total number to 1.2 million. At the end of 2005 there were an estimated 2.3 million children under 15 living with HIV (UNAIDS 2005). By end-2003, there were 1.9 million children in sub-Saharan Africa alone (UNAIDS 2004). Mother-to-child transmission accounts for over 90 per cent of the paediatric AIDS cases; the remaining 10 per cent contract the virus from contaminated blood products or non-sterile skin-piercing instruments. As noted by Phiri and Webb in chapter 11, a study in Uganda found that roughly a third of HIV-positive children died in their first year, half died by 21 months and three quarters after five years. Similarly in Malawi, some 90 per cent of HIV-infected children do not survive beyond their third birthday. Several studies have shown that the mean age of death of children born HIV-positive is 2.2 years.

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

Changes in child nutrition: HIV affects child nutrition in at least three ways. First of all, most young children born HIV-positive begin to manifest symptoms of infection during their first year of life. Many therefore suffer from stunting and wasting because of frequent attacks of diarrhoea and other opportunistic infections. In Côte d’Ivoire, a strong association was found between HIV prevalence and malnutrition among children (Pégatiénan and Blibolo 2002). Second, the large decline in income suffered by families with an AIDS-related death (chapters 7 and 8) imposes considerable cuts in food expenditure (table 2) that may affect child nutrition. In the case study on Senegal (chapter 3), Nyang and Van Ufford show that the practice of reducing food diversity has increased among HIV-affected families but not among the others. While cuts in food expenditure may be tolerable for the children of middle-income families, their impact among the poor is much more problematic and may lead to increased child malnutrition.
Third, malnutrition may also rise among children not directly affected. In chapter 11, Phiri and Webb show that nutrition is reduced for children in families that take in orphans, as the scarce family resources are redistributed among a growing number of children.

### Changes in educational achievement

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

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

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

<table>
<thead>
<tr>
<th></th>
<th>AIDS death</th>
<th>Non-AIDS death</th>
<th>No death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ugunja, Kenya</td>
<td>30.6</td>
<td>29.4</td>
<td>26.7</td>
</tr>
<tr>
<td>Côte d’Ivoire</td>
<td>27.0</td>
<td>23.8</td>
<td>11.3</td>
</tr>
</tbody>
</table>

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

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

<table>
<thead>
<tr>
<th></th>
<th>AIDS death</th>
<th>Non-AIDS death</th>
<th>No death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ugunja, Kenya</td>
<td>23.9</td>
<td>19.1</td>
<td>14.8</td>
</tr>
<tr>
<td>Côte d’Ivoire</td>
<td>27.7</td>
<td>18.5</td>
<td>16.0</td>
</tr>
<tr>
<td>Rural South Africa*</td>
<td>14.0</td>
<td>......</td>
<td>6.0</td>
</tr>
</tbody>
</table>

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

Notes: * Refers to children 14–18 years old not attending school. No significant difference was found for children in primary school and urban areas.
The data derived from the Senegalese survey (chapter 3) suggest a less pronounced, but still worrying, tendency as 6 per cent of the adults declared that, as a result of HIV, at least one of their children was dismissed from school. In addition, children with HIV may have faced problems of integration and, although no systematic discrimination was observed in schools, they were more likely to attend Koranic schools.

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

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

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

A rising number of children orphaned by AIDS

UNAIDS estimates that at the end of 2003 there were 15 million children 0–17 years old worldwide who had been orphaned by AIDS. This figure was up 3.5 million from 2001. The crisis is worst in sub-Saharan Africa, where in 2003 there were 12 million children who had lost one or both parents to AIDS. The total is expected
to reach 18 million by 2010 (UNAIDS 2004). However, as argued by Phiri and Webb in chapter 11, this figure grossly underestimates the true scale of the problem as it does not include the ‘social’ orphans. In their view, more realistic figures would be two to three times higher. When expressed in percentage terms, the rate appears even more frightening. In a low- and middle-income country with no AIDS, an average 2 per cent of children (0–18 years) are orphaned. But in 2000, in the 34 countries most affected by HIV, the average was 10.9 per cent; it was as high as 27.4 per cent in Zambia and 25.7 per cent in the Central African Republic. By 2010 it is expected to reach an average of 12.6 per cent, while in Botswana, Namibia and South Africa it will range between 30 per cent and 36 per cent, a tragedy never observed in known history, not even during the Black Death that hit medieval Europe.

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

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

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

One of the most significant impacts of HIV on orphans is not only the collapse of their families but also the disintegration of their traditional social arrangements, support structures and social relations. Orphans face mounting stigmatization in school. In Malawi, as a result of stigma and social exclusion, children tend to form
their own informal peer groups. As shown in table 4, even in a low-prevalence location such as the Sangli district of Maharashtra, they are strongly discriminated against by their peers (Verma et al. 2002). Orphans also have to assume a prematurely adult role.

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

<table>
<thead>
<tr>
<th></th>
<th>AIDS death</th>
<th>Non-AIDS death</th>
<th>No death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sangli, Maharashtra, India</td>
<td>20.1</td>
<td>2.8</td>
<td>3.1</td>
</tr>
<tr>
<td>Ugunja, Kenya</td>
<td>6.8</td>
<td>1.8</td>
<td>1.8</td>
</tr>
</tbody>
</table>

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

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

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

Economic decline and child poverty

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

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

HIV impact on the supply of social services

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

Health care

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

In Senegal, there is evidence that HIV-affected families had three times more consultations with the formal health care system than non-affected people, and that their average consultation cost was 2.2 times more than that of non-affected families.
(chapter 3). In addition, affected families paid two to seven times more than other patients to consult marabouts.

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

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

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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Côte d’Ivoire</td>
<td>0.15</td>
<td>0.33</td>
<td>0.90</td>
<td>1.25</td>
<td>1.30</td>
<td>0.43</td>
<td>0.51</td>
<td>…</td>
<td>2.80</td>
</tr>
<tr>
<td>Thailand</td>
<td>3.21</td>
<td>2.70</td>
<td>2.98</td>
<td>3.44</td>
<td>2.82</td>
<td>2.32</td>
<td>2.30</td>
<td>2.24</td>
<td>2.24</td>
</tr>
<tr>
<td>Kenya</td>
<td>…</td>
<td>…</td>
<td>…</td>
<td>…</td>
<td>…</td>
<td>…</td>
<td>…</td>
<td>…</td>
<td>1.20</td>
</tr>
</tbody>
</table>

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

In China, the problem of public care for HIV has been compounded by the dismantling of the commune-based health care system and the de facto privatization of health services. With the changes in health financing introduced since 1978, most of the rural population and about half those living in urban areas have no health insurance. Out-of-pocket payments have risen sharply and increases in user fees correlate with decreased service utilization. Because of the excessive cost of health services, antenatal care has also declined and so has hospitalization. Meanwhile, unofficial health providers tend to over-prescribe, especially injections, a trend that raises the risk of
infection (chapter 6). This approach to health-care financing is likely to hamper the adoption of appropriate screening and therapeutic approaches for HIV and AIDS.

Education

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

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

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

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

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

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

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

Prevention of HIV infection

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

These findings for Botswana and Kenya confirm the well-known discrepancy between HIV awareness and behavioural change. Yet, behavioural change was observed in Thailand following the launch in 1989 of the ‘100 per cent condom use programme’ for males going to sex workers. In Uganda, however, the relationship between IEC campaigns, behavioural change and the decline in the infection rate
is harder to prove. Indeed, it is difficult to assess the impact of information on changes in risky behaviour.

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

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

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

**Measures against the stigmatization of HIV-positive children**

Another major impact is the systematic marginalization of people affected by HIV. Discrimination takes place in every aspect of life – the workplace, schools (see above), clinics, community centres, businesses and play areas. Discrimination against HIV-positive children deprives them of many of their rights, including the right to inherit their dying parents’ possessions. Stigma clearly works against prevention. In Phuket, Thailand, fear of stigma and isolation constrains people from disclosing their status, a fact that may not help reduce the spread of the disease. In Yunnan and the rest of China, stigma is much stronger in urban areas – and some hospitals in Beijing even refuse to admit patients with HIV infection. As elsewhere, the impact of this attitude is that people living with HIV do not disclose their status and so make the work of prevention much more difficult.
Despite the gravity of the problem, this is an area in which public policy and community responses have done little and achieved even less. In 1991, awareness-raising campaigns were introduced in Thailand to try and reduce stigma against HIV-positive people, who had until then been represented in the media as a source of danger. Despite all these efforts, the situation has not significantly changed, although levels of acceptance may have improved in some areas. Clearly much more needs to be done. Interviews with stakeholders carried out in connection with research for this book identified stigma as one of the main new problems brought about by the epidemic.

Prevention of mother-to-child transmission of HIV

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

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

Access to antiretrovirals for adults

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

In 2003, WHO and UNAIDS announced a ‘3 by 5’ target – to reach 3 million people living with HIV in low- and middle-income countries with ARV therapy by
the end of 2005. By June 2005, ARV therapy coverage had more than doubled, from 400,000 to approximately 1 million. That meant that in 14 affected countries, drugs were provided to at least half of those who needed them, while in Latin America and the Caribbean, the proportion of treated patients was up to two thirds. Nevertheless, the target of treating 3 million people was unlikely to be reached by the end of the year.

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

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

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

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

Some countries have adopted a more proactive stance. South Africa’s response emphasizes reliance on communities, but also recognizes the need to provide them with financial support. As illustrated by Desmond and Gow in chapter 4, this objective was achieved by the establishment and rapid expansion of a means-tested ‘child support grant’ (Rand 170 per month) for poor children, an ‘orphan foster grant’ (Rand 530 per month) and a means-tested ‘care dependency grant’ for children with severe mental and physical problems (HIV-positive children are not included in this category). The first programme expanded rapidly (from 202,000 children in March
2001 to 3.4 million in July 2003). In March 2001, the orphan foster grant covered around 52,000 children, only 20 per cent of the estimated 250,000 orphans.

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

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

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

‘Best practice’ policy responses

Policy context

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

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

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

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

**Health policies**

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

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

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

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

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

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

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

In many countries, the spread of HIV has entailed the weakening of the PHC system, though others, such as Uganda, have managed to expand their basic health
infrastructure, despite the HIV epidemic. Chapter 10 shows that as HIV has spread, immunization rates and maternal and child health services have deteriorated in several African countries.

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

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

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

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

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

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

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

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

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

Children orphaned and abandoned due to HIV and AIDS

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

Some of the problems encountered in introducing ‘best practice’ interventions or in expanding their scale are technical, but others fail because governments may be reluctant to promote them if they implicitly criticize past approaches or lack of action. In chapter 11, Phiri and Webb identify the following alternative care options:
Institutional care: Placing such children in state or faith-based orphanages is seldom the preferred option, except when children have been severely abused or require highly specialized assistance. However, orphanages often appeal to the relatives of poor children because they are perceived to be well funded and thus able to solve children’s material needs. Several studies show that the majority of children in orphanages were placed there not so much due to the death of a parent as because of poverty or divorce. These institutions, however, suffer from well-known problems: first of all, their unit costs are high ($600–$2,000 per child/year) so that it is impossible to replicate such an approach on the scale required by the current HIV emergency. In addition, institutional care does not provide the holistic care and environment that a family setting offers. As a result, children in institutions lack basic social, cultural and parenting skills, have relational difficulties and have problems adjusting to the outside world when they leave the orphanage. Moreover, they only have tenuous ties with the clans and villages from which they originate. This lack of connectedness is particularly important in Africa and Asia, and is an important component of the personal identity of the child.

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

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

Community-based foster families: Sometimes a foster mother (or a group of mothers acting collectively) takes up to six children in a house provided by the community. The foster mother receives from the state or a large NGO (e.g. Uganda Women’s Effort to Save Orphans (UNESCO) a child support or foster grant for each child as well as a small allowance for herself. At times, the transfer of foster grants by state institutions faces administrative and eligibility problems, as in the case of South Africa where abandoned children may lack identification documents and cannot easily apply for support. Some administrative simplification is therefore required. With this approach, siblings are kept together and community structures are involved in the monitoring of various foster mothers, in ensuring access to services and – whenever feasible – in providing psychological help and legal counselling to
children. Large NGOs (as, again, UWESO) can provide additional resources for food, school fees ($35 a year for primary school and $75 for secondary), health costs and clothing. When these resources are scarce, the communities prioritize the neediest children.

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

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

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

The psychosocial needs of orphans and HIV-affected children are often neglected. HIV causes not only death, hunger and other material deprivation among orphans, but also a sense of abandonment, depression and rejection. Children do not verbalize their feelings. They may become withdrawn, play truant, antisocial and prone to depression in adult life. Older children may get into conflict with their
foster parents, become aggressive and join gangs of street children. In several cases, entire cohorts of young people will grow up in situations in which mental ill health will be rife.

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

**Economic support and welfare transfers to impoverished families**

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

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

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

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

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

The political economy of the response to AIDS

One of the main reasons for the limited success in the response to AIDS is the limited commitment of most governments to fight the spread of the disease and to mitigate its impact. Most HIV-affected countries have been accused of lacking political will and commitment to respond to AIDS. However, as is well known, this has not always been the case. Countries such as Senegal, Thailand and, to some extent, Uganda were able to control adult prevalence at low levels or to reduce its level after an initial rise. What explains, then, the openness and directness with which the AIDS problem has been dealt with in some nations, while in others with
similar structural characteristics the AIDS problem has been denied, ignored or trivialized? And, why have some countries allocated substantial resources to the control and mitigation of the long-term effects of HIV, while in others the burden of responding to the epidemic has been shifted to families and communities? Do these differences depend on the structural characteristics of the countries concerned? Or on the different perceptions of self-interest by the elites? Most explanations of the differences in policy concern the presence or absence of charismatic leaders. But these explanations are not very convincing.

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

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

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

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

A committed and competent bureaucracy and cohesive civil society are essential for the success of any collective undertaking. In China, the dismantling of the
public health services, ineffective STI control and the difficulties in communicating between central, local and village authorities proved to be major obstacles to an early and effective national response to the epidemic.

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

References


Chapter 2
The Impact of HIV and AIDS on Children: Lights and Shadows in the ‘Successful Case’ of Uganda

Robert Basaza, Darlison Kaija and Dorothy Ochola-Odongo

Introduction

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

Table 1 shows the numbers of children and adults affected by the epidemic. While the number of people infected with HIV decreased over the two years, the number of people who died increased, as they succumbed to the virus caught 7 to 10 years before. AIDS is the leading cause of mortality in Uganda and is responsible for about 12 per cent of all deaths in the country.
Table 1. Estimates of AIDS epidemic in Uganda, 1999 and 2000

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

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

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

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

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

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

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

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

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

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

Sources: STI/ACP Surveillance Report 2001 and other previous MoH Uganda reports.
Social epidemiology of HIV

Variations in HIV prevalence

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

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

Figure 2. Age of Ugandan AIDS cases
ratio of men to women infected was close to 1:1, but a decade later, a study showed that females under 25 were twice or three times more likely to be HIV-positive than men (Kayita and Kyakulaga 1997). Other studies show similar trends. Data indicate that the difference in prevalence between the sexes is particularly marked in the 15–19 year age group, when girls are three to six times more likely to be infected than boys. The gap reduces somewhat between the ages of 24 to 29, but after the age of 30, on average males have a higher prevalence than females.

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

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

![Graph showing distribution of adult AIDS cases by age and sex](image)

**Surveillance systems**

Seroprevalence rates in Uganda are derived from three sources. First, there are population-based cohort studies in several districts. Second, there is the AIDS information centre (AIC), which compiles data from voluntary counselling and testing (VCT) in various parts of the country. Data from AIC have helped to identify the vulnerable groups, predict the future direction of the epidemic and prioritize interventions and target groups. Third, there are the 15 antenatal sentinel sites. Although they only provide data on women, the 250–600 blood samples collected quarterly give a realistic picture of the geographical patterns of HIV prevalence and its relationship to STI rates.
Figure 4 highlights how the epidemic has evolved, peaking in 1992 and then gradually declining.

**AIDS case surveillance**

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

**Paediatric AIDS case reports**

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

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

Main routes of transmission

According to the Ministry of Health (MoH) 1997 surveillance report on sexually transmitted infections (STIs) and HIV (MoH 1997), the main routes of HIV transmission in Uganda include:
1. Heterosexual contact with an infected partner (75–80 per cent).
2. Mother-to-child transmission of HIV through birth or breastfeeding (18–22 per cent).
3. Infected blood, blood products and septic conditions in health facilities (less than 2 per cent).
4. Use of non-sterile sharp piercing instruments (less than 1 per cent).

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

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

Circumcision: Some ethnic groups, such as the Bakonjo and Bamba in Western Uganda and Sabiny and Bagisu in Eastern Uganda (10 per cent of the population), initiate young men into adulthood through ritual circumcision. These traditional operations are generally carried out during adolescence, often after the onset of puberty, and the sterility and safety of the instruments used is a cause for concern.
In addition, the male circumcision ceremonies are often accompanied by sex with multiple partners (Olowo-Freers and Barton 1992). Muslim communities, who constitute about 10 per cent of the country’s total population, circumcise males according to the precepts of their religion. The procedure is usually done in hospital under sterile conditions, thus limiting the potential for infection.

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

**Risk behaviour**

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

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

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

**Refugees and internally displaced persons (IDPs):** Refugees and IDPs, who are mainly women, children and the elderly, usually live in temporary rural camps. Although data on HIV prevalence in such groups are not available, they are considered at risk due to the social, economic and psychological breakdown so often
prevalent in the camps. Risk factors include transactional sex to escape to safety, gain access to shelter or other services, and the deliberate use by men of sex as a weapon to demonstrate power and inflict pain and humiliation on women, children and other men (UAC and UNAIDS 2000).

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

Other social risk factors

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

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

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

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

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

Impact on children’s health

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

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

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

Source: Various reports.

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

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

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

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

![Graph showing reported illness by cause for children in six districts in Uganda](image)


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

**Impact on the health sector**

In Uganda, as in the rest of sub-Saharan Africa, AIDS is the leading cause of mortality, ahead of malaria, tuberculosis and other diseases (chapter 11). According to the MoH Management Information System, AIDS is responsible for up to 12 per cent of deaths in Uganda, is a leading killer of adults aged 15–49 years, and the fourth leading cause of death among under-five children. Only about 1.2 per cent of the health budget is specifically dedicated to HIV, though a considerable part of the general health infrastructure is used for care of HIV-infected patients. As in Botswana, the Democratic Republic of the Congo, Rwanda, South Africa and Zambia, about half the available hospital beds are occupied by those with AIDS and related opportunistic infections.
Only 49 per cent of Ugandans reside within 5km of a health facility, and only two fifths (40 per cent) of the units have achieved a minimum staffing norm. The ratio of doctors to people in Uganda is 1:18,000, while that of nurses is 1:3,000. The problems of staffing and access to health services are being addressed through the creation of health subdistricts. On 1 March 2001, cost-sharing in public facilities was abolished because it was found that 43 per cent of the people in rural areas and 36 per cent in urban areas could not seek health care due to lack of money. In some districts, up to 71 per cent could not afford to access health care (Ministry of Finance, Planning and Economic Development 2001).

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

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

<table>
<thead>
<tr>
<th>Disease</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>26</td>
<td>72</td>
</tr>
<tr>
<td>Alcohol</td>
<td>6</td>
<td>17</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>36</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>


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

### Impact on education

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

Table 5. Impact of HIV on schoolchildren in Uganda

<table>
<thead>
<tr>
<th>Year</th>
<th>All Primary Schoolchildren</th>
<th>All Orphans</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Enrolment</td>
<td>Dropouts</td>
</tr>
<tr>
<td>1995</td>
<td>4,357</td>
<td>2,794</td>
</tr>
<tr>
<td>1996</td>
<td>5,020</td>
<td>3,492</td>
</tr>
<tr>
<td>1997</td>
<td>6,403</td>
<td>4,871</td>
</tr>
<tr>
<td>1998</td>
<td>6,403</td>
<td>4,822</td>
</tr>
<tr>
<td>1999</td>
<td>6,414</td>
<td>4,879</td>
</tr>
</tbody>
</table>


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

HIV, of course, affects the teacher and pupil population. Absenteeism from work by professional and support staff is mainly due to intermittent sickness, fear, stigmatization, worries, distress and apathy. There are no reliable estimates of the extent of teacher absenteeism due to HIV, but attrition from service due to death is better documented (table 6). The rate is higher in secondary than in primary schools (average 3 per cent for primary and 4 per cent for secondary) over a four-year period. The HIV epidemic caused the death of 450 teachers in the year 2000, as compared to 53 in 1995, an increase of over 8.5 times.
Quality of education: The impact of HIV on the quality of education is demonstrated by the lowered productivity and reduced efficiency of staff due to intermittent sickness, absenteeism and depression. It is also estimated by UNAIDS and UNICEF that in 2000, out of 5 million primary school students, 81,000 lost a teacher due to AIDS. This has increased the workload of the remaining teachers, in addition to their extra responsibilities resulting from the push towards UPE. Over 90 per cent of children are in government-aided primary schools. The government meets the statutory primary school fees for a maximum of four children per family and also undertakes to provide building materials not locally available such as iron sheets, timber, cement and nails, in addition to instructional materials and payment of teachers’ wages.

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

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

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

Table 7. Socioeconomic impact of HIV and AIDS on orphans

<table>
<thead>
<tr>
<th>Level</th>
<th>Potential Socioeconomic Impacts</th>
<th>Mitigating/Aggravating Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Short-term</td>
<td>Long-term</td>
</tr>
<tr>
<td>Orphan</td>
<td>• Loss of inheritance</td>
<td>• Reduced quality of human capital</td>
</tr>
<tr>
<td></td>
<td>• Reduced health, nutrition</td>
<td>• Entrenched poverty</td>
</tr>
<tr>
<td></td>
<td>• Reduced school attendance</td>
<td>• Increased poverty</td>
</tr>
<tr>
<td></td>
<td>• Increased labour</td>
<td>• Number, age, health of orphans</td>
</tr>
<tr>
<td></td>
<td>• Increased social isolation,</td>
<td>• Cause of death of parent(s)</td>
</tr>
<tr>
<td></td>
<td>vulnerability and abuse</td>
<td>• Family or non-family</td>
</tr>
<tr>
<td></td>
<td>• Increased homelessness</td>
<td>living arrangement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Head of household</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Availability of aid</td>
</tr>
<tr>
<td>Family</td>
<td>• Increased dependency ratio</td>
<td>• Previous family income and assets</td>
</tr>
<tr>
<td></td>
<td>• Increased poverty</td>
<td>• Number, age, health of orphans</td>
</tr>
<tr>
<td></td>
<td>• Increased workload</td>
<td>• Cause of death of parent(s)</td>
</tr>
<tr>
<td></td>
<td>• Reduced per person food</td>
<td>• Head of household</td>
</tr>
<tr>
<td></td>
<td>consumption and uptake of services (education, health)</td>
<td>• Availability of aid</td>
</tr>
<tr>
<td>Community and nation</td>
<td>• Increased poverty</td>
<td>• Historical economic strength</td>
</tr>
<tr>
<td></td>
<td>• Reduced child health, school enrolment</td>
<td>• Access to services</td>
</tr>
<tr>
<td></td>
<td>• Increased inequalities</td>
<td>• Availability of assistance</td>
</tr>
<tr>
<td></td>
<td>• Increased crime, homelessness</td>
<td>• Effective anti-poverty</td>
</tr>
<tr>
<td></td>
<td>• Increased social instability</td>
<td>programmes</td>
</tr>
<tr>
<td></td>
<td>• Changes in cultural practices</td>
<td>• Effective programmes</td>
</tr>
<tr>
<td></td>
<td>• Diversion of resources</td>
<td>for orphans</td>
</tr>
<tr>
<td></td>
<td>for orphan care</td>
<td></td>
</tr>
</tbody>
</table>

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

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

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

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

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

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

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

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

Interventions against HIV and AIDS

President’s initiative and formulation of AIDS control programmes

The country’s response to HIV and AIDS between 1982 and 1986 was largely confined to the health sector and handled like other epidemics. Most Ugandans thought of the disease as witchcraft, and later as a disease of the immoral, which led to stigmatization of people living with HIV (PLHIV). In 1986, a new government came to power and the new Minister of Health announced the existence
of HIV and AIDS in the country during the World Health Assembly in Geneva. This served as a springboard for nationwide mass awareness campaigns spearheaded by President Museveni. He referred to the menace of AIDS in his speeches as he toured the country, urging his audience to avoid reckless sexual behaviour to minimize the spread of HIV. The First Lady supported this campaign by urging people to assist families affected by HIV. She later founded the organization Uganda Women’s Effort to Save Orphans (UWESO), which was originally founded to assist war orphans, but quickly expanded to include those orphaned by AIDS. Consultations on the multi-sectoral approach, spearheaded by the President, resulted in the formulation of the National AIDS Commission in 1992. The President himself chaired initial meetings that led to the formation of UAC. Every politician was required to campaign against HIV at all mass gatherings. This slowly demystified the disease as people gained more insight into their vulnerability to infection and prevention measures.

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

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

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

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

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

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

<table>
<thead>
<tr>
<th>Prevention indicator</th>
<th>Mbarara</th>
<th>Mpigi</th>
<th>Masindi</th>
<th>Pallisa</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of preventive measures</td>
<td>77.9</td>
<td>78.7</td>
<td>84.8</td>
<td>81.1</td>
</tr>
<tr>
<td>Reported non-regular sexual partners</td>
<td>6.6</td>
<td>8.7</td>
<td>7.3</td>
<td>8.6</td>
</tr>
<tr>
<td>Reported condom use with non-regular partners</td>
<td>31.9</td>
<td>48.0</td>
<td>54.8</td>
<td>71.2</td>
</tr>
<tr>
<td>Reported incidence of urethritis (for men)</td>
<td>12.0</td>
<td>14.2</td>
<td>11.8</td>
<td>8.9</td>
</tr>
</tbody>
</table>

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

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

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

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

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

Prevention of blood-borne HIV transmission: In order to reduce the transmission of HIV and other diseases through contaminated blood, the MoH started the Uganda Blood Transfusion Services Project in 1987. Largely funded from the
outset by the European Union, the project was due to be 100 per cent funded by the government from 2004 onwards. More than two thirds of those given blood are children under 12, so safe blood transfusion is a key strategy in prevention of HIV in children. The service is considered to be the best in Africa, with 98 per cent of the blood being safe. Since 1997, the service has been a regional training centre for anglophone Africa.

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

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

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

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

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

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

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

**Antiretroviral therapy**

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

Uganda is participating in the global ‘3 by 5’ Initiative to deliver antiretroviral therapy to 3 million AIDS patients worldwide by the end of 2005, the target for Uganda being 60,000 patients. The major hindrance to expansion of ART had been prices, but following global advocacy to reduce costs for low- and middle-income countries, there has been increased access. As of April 2004, the cheapest triple combination pre-qualified by WHO cost $244 per patient per year (Médecins Sans Frontières 2004). Over 80 per cent of clients paid for their treatment, but the government managed to leverage resources through a number of mechanisms and initiatives in an effort to provide free ART to the population. Funding programmes include: $3 million from the World Bank (MAP Project) to treat 6,000 patients for one year; $10.6 million from the Global Fund to Fight AIDS, Tuberculosis and Malaria for the period 2004–2006; and another $36 million from the fund for 2005–2007. The US President’s Emergency Plan for AIDS Relief (PEPFAR) was initiated
in 2004 and provides funds for treatment of 60,000 people over five years. This is being implemented through four organizations: Catholic Relief Services will treat 2,700 people in seven health facilities during the first year and then scale up over five years; The AIDS Support Organization (TASO) will treat 3,000 in the first year, 7,000 in the second year and 10,000 in the third year in TASO centres; a further 1,300 will be treated by the Mildmay Project; and another 200 by the Rakai Project. In addition, a number of private employers treat their employees and several government ministries such as Public Service and Finance have plans to provide ART to their staff.

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

Prevention of mother-to-child transmission of HIV

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

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

<table>
<thead>
<tr>
<th>Year</th>
<th>Planned sites</th>
<th>Cumulative number of districts with PMTCT (planned)</th>
<th>Actual districts with at least one site (cumulative)</th>
<th>Coverage by district</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(modelling phase)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>8</td>
<td>11</td>
<td>4</td>
<td>8%</td>
</tr>
<tr>
<td>2002</td>
<td>17</td>
<td>28</td>
<td>22</td>
<td>40%</td>
</tr>
<tr>
<td>2003</td>
<td>10</td>
<td>38</td>
<td>34</td>
<td>61%</td>
</tr>
<tr>
<td>2004</td>
<td>18</td>
<td>56</td>
<td>56</td>
<td>100%</td>
</tr>
</tbody>
</table>
This rapid expansion has been achieved in partnership with other development partners. As of end-2004, the cumulative number of women and children benefiting from the programme was as follows: 512,090 pregnant women had accessed antenatal care services, including HIV testing, at PMTCT sites; 394,642 (80 per cent) of these women were counselled for HIV; 240,944 accepted HIV testing and 25,090 (10 per cent) tested HIV positive. A total of 13,866 HIV-positive pregnant women received prophylactic ARVs, together with 8,719 babies. Data on the number of children treated with ARVs is incomplete, as not all women who receive nevirapine during antenatal visits return to deliver at the health facility and some may have miscarriages. Below is a graph showing the overall performance of the PMTCT programme from January 2000 to end-2004.

Figure 6. Performance of PMTCT programme 2000–2004

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

Table 10. Cost of antiretrovirals for PMTCT of HIV

<table>
<thead>
<tr>
<th>Number of mother–baby pairs</th>
<th>Modified Thai1 $</th>
<th>PETRA Arm A 2 $</th>
<th>Nevirapine $</th>
</tr>
</thead>
<tbody>
<tr>
<td>One mother–baby pair</td>
<td>125.0</td>
<td>90.0</td>
<td>1.0</td>
</tr>
<tr>
<td>109,200 mother–baby pairs</td>
<td>13,650,000</td>
<td>9,828,000</td>
<td>109,200</td>
</tr>
<tr>
<td>54,600 mother–baby pairs</td>
<td>6,825,000</td>
<td>4,914,000</td>
<td>54,600</td>
</tr>
</tbody>
</table>


There are still a number of cultural and systemic constraints to preventing mother-to-child transmission of HIV. Moreover, breastfeeding is the norm for infants in Uganda and there are few alternatives, particularly in rural areas, so where large
family sizes are traditionally associated with security, prevention of MTCT may encourage HIV-positive couples to have children. The limitations of Uganda’s health system, which covers 85 hospitals and 1,800 health centres (dispensaries, subdispensaries and maternity centres), mean that there is inadequate medical supervision for mothers who give birth at home, and there are few staff available to offer counselling, testing and follow-up of clients after delivery. There are no counselling rooms in hospitals and insufficient laboratory facilities to monitor women who are on antiretroviral therapy.

Interventions in the education sector

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

- **The Early Life Skills Initiative**, which trains young people in skills such as interpersonal relationships; self awareness and self-esteem; problem-solving; effective communication; decision-making; negotiation skills; resisting peer pressure; critical thinking; and formation of friendships. The initiative was developed to bridge the gap between high levels of knowledge and awareness about HIV and AIDS and lagging behaviour change.

- **The UNICEF-supported Sara Communication Initiative**, which aims to develop girls’ life skills.

- **IEC in support of reproductive health** is intended to impart knowledge and skills about all aspects of reproductive health, not only STIs and HIV transmission.

- **Sensitization seminars** on the HIV epidemic for the 500-strong Ministry of Education and Sports workforce. However, lack of policy, plan and funding inhibited effective sensitization and advocacy relevant to the epidemic.

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

**The District Response Initiative**

The goal of the District Response Initiative is to create HIV-competent communities where all elements of society are enabled to appreciate the reality of the epidemic,
take action to prevent its spread, improve the quality of lives of infected people and support affected people and their families.

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

Uganda’s National Programme of Action for Children

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

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

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

The Government

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

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


The social welfare sector

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

The education sector

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

In April 2001, the sector produced an HIV strategic plan 2000/1–2005/6, which focuses on key intervention areas, such as developing policy guidelines that promote
prevention and mitigation of the epidemic, HIV education, advocacy and mobilization, including establishment of VCT services in institutions, and welfare programmes for HIV-positive staff and children orphaned by AIDS. The plan also foresees setting up education bursaries/scholarships and material support for schoolchildren, particularly those orphaned by AIDS. The orphan scheme will initiate income-generating activities such as poultry, horticulture and arts and craft.

The health sector

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

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

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

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

Curative services, which cover care of HIV-related diseases, account for over 60 per cent of all health expenditure. Less than 10 per cent of the total health budget is allocated to HIV programmes.
In order to increase access to health care, in March 2001, MoH abolished user fees (which had been in place for the past decade) in all government-owned units other than the private wings. The government has established secondary-level referral facilities (with an operating theatre, an anaesthetist, a doctor and a public health nurse) in all counties to cover an average population of 100,000 people. This has led to construction of 134 referral health centres, which are largely mini-hospitals. Most of the recruited staff have been posted to rural health facilities and NGO facilities located in underserved rural areas. The government provided grants, covering up to 50 per cent of recurrent expenses, to NGO hospitals and health centres. The sector plan provides for construction of a health centre for every 5,000 people in order to increase geographical access.

NGOs, CBOs and international agencies

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

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

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

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

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

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

- **Voluntary and anonymous HIV counselling and testing.** This service is offered Monday through Saturday at a minimal fee. Counselling is a prerequisite for testing, and there is strict confidentiality, with no written record of the results given to clients.

- **Detection and management of other STIs.** All clients who consent to take the HIV test are also screened for syphilis and treated where necessary. Clients may be tested for syphilis only if they wish.

- **Condom education and distribution.**

- **Information and counselling on family planning.** All clients who come to AIC receive information, education and counselling. Counsellors and reproductive health volunteers help clients make informed decisions about which family planning methods to use. AIC provides clients with pills, condoms, spermicides, injections and referrals for other methods. Pregnancy tests are also done at no cost.

- **TB education and referrals.** Information and counselling on TB is given to all clients who seek VCT services.

- **Psychosocial and medical services** are offered through the Post Test Club.

**TASO**: TASO was the first indigenous community-based organization, founded in 1987 by a group of 16 committed volunteers, most of whom were directly affected
by HIV and many of whom have since died. TASO has grown into one of the biggest organized national responses to the HIV epidemic, with eight branches countrywide. It works closely with AIC and other related institutions. TASO receives funding from MoH, international agencies such as the United Kingdom Department for International Development (DFID), and the European Union.

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

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

**Traditional healers**

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

**The role of the extended family**

The African tradition of the extended family providing a safety net for members in time of need is declining fast because of poverty and immediate family demands. A
study by the Medical Research Council (UK), based on data collected by counsellors, on the care given to 30 patients diagnosed with AIDS by their families (17 women, 13 men), showed that 27 of the 30 cases received limited care due to lack of food, lack of money for medication and other family responsibilities. For the 17 clients who died during the study period, records of 7 cases show that other relatives were asked to help with care, but refused on grounds of poverty or other commitments. In only one case did the extended family provide assistance for the funeral.

The business sector

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

Lessons learned

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

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

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

The involvement of local and international NGOs, CBOs and FBOs in all areas of service-delivery and policymaking has brought all key stakeholders on board and achieved wide coverage. Communities and individual families have also been
involved in the control, treatment and mitigation of the consequences of HIV. Although these are very good lessons for other countries, Uganda still has large gaps that need to be addressed if the current momentum is to be kept on track.

**Recommendations**

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

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

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

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

Despite the contributions by the government, NGOs and donor community towards the control and treatment of AIDS, the country still faces limitations in resources to combat the pandemic. Efforts must be intensified to mobilize resources from both within and outside the country. This should also include efforts to foster regional groups, such as the Great Lakes Initiative, to increase the availability of interventions, including access to ART and condoms, through economies of scale. By encouraging regional groupings, there can be sharing of experience among the members and scaling-up of successful practices.
There has to date been limited use of economic modelling when designing programmes to respond to AIDS. UAC, in collaboration with UNAIDS, line ministries and agencies, could consider convening a working party composed of multi-disciplinary professionals, with a critical mass of health economists, in order to address these policy gaps. There is a need to carry out further research on the cost-effectiveness of intervention programmes such as large-scale use of ART. The country also urgently needs to develop a policy on how to administer and use ART, for the guidance of health workers and the public at large.

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

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**Notes**

1 Data on attrition and mortality for years other than 1995–1998 were not available.

2 Teacher attrition includes leaving the service through resignation, leaving without notice, death or retirement. Transfers, secondment or leaving for training are not regarded as attrition.

3 Based on a WHO estimate that HIV/AIDS accounted for 20.6% of the mortality in sub-Saharan Africa in 1999.
Chapter 3
The Socioeconomic Impact of HIV on Children in a Low-Prevalence Context: the Case of Senegal
Cheikh Ibrahima Niang and Paul Quarles Van Ufford

Introduction
This chapter examines the socioeconomic impacts of HIV on children in Senegal as well as the results of the policies being implemented in response to the virus. The primary data presented were collected at seven research sites across the country, while the secondary data were gathered mainly in Dakar. The first part of the chapter briefly introduces the current situation of HIV and AIDS in Senegal, giving some basic data and an analysis of the major factors that are likely to have contributed to the low and stable HIV prevalence, characteristic of this West African country. The next part outlines the research questions and the methodology employed to carry out what was a rather complex research project among vulnerable HIV-infected and affected adults and children. The third section presents the main research findings, analysing the socioeconomic impact of HIV at the national, community/household and individual levels. The final part summarizes the major conclusions drawn from the answers to the initial research questions.

HIV in Senegal
In the context of sub-Saharan Africa, the case of Senegal is a rather unique one, in that the HIV infection rate has been both low and stable since the first cases were detected in the mid-1980s (Meda et al. 1998). Whereas for sub-Saharan Africa the average HIV prevalence in the general population is about 8 per cent, it is 1.4 per cent in Senegal (ONUSIDA 2000a). However, even though the national average rate is low, there are major variations between the social groups from which the serological samples have been taken. Thus, from the outbreak of the epidemic, high prevalence has been recorded among sex workers; a study carried out in 1989 found a rate of 44.8 per cent among sex workers in Ziguinchor and rates higher than 30 per cent were noted in Kaolack (Sankale et al. 1989). As shown in table 1, a decade later sex workers continued to reveal the highest prevalence whereas pregnant women had the lowest.¹
The distribution by sex of the number of people infected with HIV shows a comparatively lower number of infected women. According to the estimates for the year 2000, among the 80,000 people infected with HIV in Senegal, 35,000 were women. The ratio of women to men has gradually increased since the early 1990s. Whereas in 1987 HIV-positive women represented only 10 per cent of the total, this percentage had already risen to 30 per cent in 1992 and in 2002 was estimated to be slightly less than 50 per cent (table 2).

At end-2004, the estimated number of children living with HIV was 3,000, the same as it had been in 2000 (ONUSIDA/OMS, 2000b; UNAIDS 2004). The breakdown by region of HIV prevalence among adults, women and children is presented in table 2. It appears that the regions of Kaolack and Fatick are relatively hardest hit in terms of the number of infected persons in comparison with their share of the total population.

Table 1. HIV prevalence among specific groups (estimates for 1999)

<table>
<thead>
<tr>
<th>Population</th>
<th>HIV prevalence %</th>
</tr>
</thead>
<tbody>
<tr>
<td>General population</td>
<td>1.4</td>
</tr>
<tr>
<td>Pregnant women</td>
<td>1.2</td>
</tr>
<tr>
<td>Prisoners</td>
<td>3</td>
</tr>
<tr>
<td>STI patients</td>
<td>3</td>
</tr>
<tr>
<td>Tuberculosis patients</td>
<td>10</td>
</tr>
<tr>
<td>Hospital prevalence</td>
<td>15</td>
</tr>
<tr>
<td>Sex professionals</td>
<td>20</td>
</tr>
</tbody>
</table>

Source: ONUSIDA/OMS 2000b.

Table 2. Breakdown of HIV prevalence by region for adults, women and children (estimates for 2000)

<table>
<thead>
<tr>
<th>Region</th>
<th>% of total population</th>
<th>Total</th>
<th>Adults</th>
<th>Children (0–15 years)</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dakar</td>
<td>24%</td>
<td>20,000</td>
<td>25%</td>
<td>19,400</td>
<td>600</td>
</tr>
<tr>
<td>Kaolack</td>
<td>12%</td>
<td>14,000</td>
<td>18%</td>
<td>13,600</td>
<td>400</td>
</tr>
<tr>
<td>Thiès</td>
<td>14%</td>
<td>8,800</td>
<td>11%</td>
<td>8,500</td>
<td>300</td>
</tr>
<tr>
<td>Fatick</td>
<td>6%</td>
<td>7,700</td>
<td>10%</td>
<td>7,400</td>
<td>300</td>
</tr>
<tr>
<td>Diourbel</td>
<td>9%</td>
<td>7,200</td>
<td>9%</td>
<td>7,000</td>
<td>200</td>
</tr>
<tr>
<td>Saint-Louis</td>
<td>9%</td>
<td>5,800</td>
<td>7%</td>
<td>5,500</td>
<td>300</td>
</tr>
<tr>
<td>Louga</td>
<td>6%</td>
<td>5,500</td>
<td>7%</td>
<td>5,200</td>
<td>300</td>
</tr>
<tr>
<td>Kolda</td>
<td>8%</td>
<td>4,500</td>
<td>6%</td>
<td>4,300</td>
<td>200</td>
</tr>
<tr>
<td>Ziguinchor</td>
<td>6%</td>
<td>3,500</td>
<td>4%</td>
<td>3,300</td>
<td>200</td>
</tr>
<tr>
<td>Tambacounda</td>
<td>5%</td>
<td>3,000</td>
<td>4%</td>
<td>2,800</td>
<td>200</td>
</tr>
<tr>
<td>Senegal</td>
<td>80,000</td>
<td>77,000</td>
<td>3,000</td>
<td>35,000</td>
<td></td>
</tr>
</tbody>
</table>

There is much higher prevalence in areas with high emigration rates. In northern Senegal, for instance, rates of 23 per cent were observed among the adult populations of some villages where links between prior emigration and HIV have been clearly and strongly established (Kane et al. 1993).

On the whole, the number of people living with HIV has remained comparatively low, although increases were recorded for the years 1986–1988, 1992–1994 and 1996–1997. From the outbreak of the epidemic until 2000, the estimated cumulative total number of people who died of HIV-related illnesses was 30,000, 5,000 of them in 2000.

The low intensity of the HIV epidemic is reflected in the forecasts by the National Programme against HIV/AIDS. While previous forecasts for sub-Saharan Africa turned out to underestimate the spread of HIV (in 1999 there were 23.5 million people living with HIV against the 9 million forecast in 1990), the forecasts for Senegal have proven to be overestimates. In 1997 it was predicted that the HIV prevalence would be 2.3 per cent in 2000, but that year the estimate had to be revised downwards to 1.4 per cent (table 1). At the end of 2003, UNAIDS estimated the rate to be 0.8 per cent (UNAIDS 2004).

Low and stable prevalence and prevention policies: The low and stable HIV prevalence has led some researchers to suspect that there are biological factors that have limited the spread of HIV (Mboup 1996). However, this hypothesis does not seem to account for the epidemiological situation particular to Senegal (Meda et al. 1998).

Social and cultural hypotheses have also been put forward including, for instance, the widespread practice of male circumcision, the generally low consumption of alcohol, and the strong religious values that encourage the control of sexuality. In addition, the relatively late age of first sexual activity, the low level of extramarital sexual relations, and high condom use during extramarital sexual relations, especially commercial sex, have been identified as important factors. However, some authors have emphasised that this apparently favourable behavioural context has been under increasing pressure – as elsewhere in Africa – in the wake of migration, urban development and modernization (ONUSIDA/OMS 2000c).

That is why at least part of the explanation for the low and stable HIV prevalence is considered to be the policy response. In particular, strenuous efforts in the fields of STI control and treatment, condom promotion, and early and sustained commitment by political and religious leaders have had a considerable effect in limiting the general population’s exposure to HIV.

The public health policy is based on basic service delivery and information for high-risk groups, a strong tradition of community engagement in favour of health and development, and positive dialogue with faith and community leaders at all levels, according to their specific spheres of influence. Thus, parliamentarians were
expected to work for the campaign against HIV during the state budget voting sessions, whereas faith leaders were asked to talk about abstinence and fidelity (ONUSIDA/OMS 2000c). A guide on *Islam and HIV/AIDS* was developed, propagating the advantageous role of Islamic prescriptions in the prevention of HIV and at the same time recommending religious sermons and lectures to better protect people. The consensus about condoms did not involve faith leaders’ support for the circulation of condoms, but it did help avoid ‘a war against condoms’. In fact, the success of the promotion of condom use is often interpreted as being the result of an approach that integrates cultural values.

A recent document on best practices in the response to AIDS in Senegal identifies the following elements as being important in Senegal’s response to the epidemic: the existence of a policy of legalization of sex work and STI treatment of sex workers since well before the outbreak of the epidemic; a secure blood transfusion policy since 1970; the integration of STI treatment in family planning activities from the early 1980s; health sector reforms that favour access to care, and the participation of the population in management of the health system; the existence of a strong network of young people’s and women’s movements as well as faith-based structures receptive to social mobilization activities (Groupe Thematique ONUSIDA/Senegal 2001). In terms of general approaches, the report underlines the effectiveness of having a cross-sectoral and integrated approach and intervening early enough in the onset of the epidemic. Senegal had already instituted an HIV sentinel system by the end of the 1980s. Ever since, the number of sentinel sites and the diversity of target groups have progressively increased. In 1997, Senegal served as a pilot country for the implementation of regular social and behavioural surveys. The combined collection of biological and behavioural data has been accompanied by consistent capacity building. In fact, the national laboratory for bacteriology and virology has become a reference centre for sub-Saharan Africa. A more recent illustration of the proactive attitude towards new developments in HIV prevention and treatment is the fact that Senegal is one of the first African countries to have undertaken negotiations with pharmaceutical companies and obtained substantial price reductions for antiretroviral drugs.

The analysis of best practices also highlights, among other factors, the focus of interventions on specific groups (high-risk and vulnerable groups, faith and community leaders, journalists, etc.), the attention paid to the social and cultural context, the National Programme for the Fight against HIV/AIDS, and the strong political commitment at the highest level.

**Research methodology**

To analyse the socioeconomic consequences of HIV for children, it was assumed on the basis of the literature survey that HIV might have an impact on:
• physical capital (property, financial savings, investments, production);
• social capital (social networks, solidarity arrangements, family structures);
• human capital (education, health, nutrition).

These types of capital exist at the individual, household (nuclear and extended family) and community levels (social groups, networks, community-based organizations) and therefore constitute a relevant framework for analysis (cf. Bollinger, Stover and Diop 1999). In order to take into account the variety of ways in which HIV impacts on children, the survey design included children who live with HIV and children whose parent(s) live with HIV (often these were the same children).

The research methodology involved primary and secondary data collection. The primary data were collected between June and September 2001 at seven research sites, the main characteristics of which are shown in table 3. The secondary data were mainly used to analyse national level social, demographic, health and economic indicators.

<table>
<thead>
<tr>
<th>Locality</th>
<th>HIV prevalence %</th>
<th>Ethnic groups</th>
<th>Other features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dakar</td>
<td>1.3</td>
<td>Cosmopolitan city</td>
<td>Capital of the country; high population growth; substantial socioeconomic inequality</td>
</tr>
<tr>
<td></td>
<td></td>
<td>– predominance of Wolof</td>
<td></td>
</tr>
<tr>
<td>Kaolack</td>
<td>1.8</td>
<td>Wolof, Serere</td>
<td>Major commercial crossroads near border with Gambia; frequent movements of traders, seasonal workers, farmers, sex workers, etc.</td>
</tr>
<tr>
<td>Thiès</td>
<td>1</td>
<td>Wolof, Serere</td>
<td>Mining and tourist region (frequent population movements)</td>
</tr>
<tr>
<td>Mbour</td>
<td></td>
<td>Serere, Wolof, Mandinka</td>
<td>Heavy influx of tourists, seasonal fishermen and sex workers; also drug trafficking</td>
</tr>
<tr>
<td>Saint-Louis</td>
<td>0.9</td>
<td>Wolof, Toucouleur</td>
<td>After a long spell of decline (1960–1990), the city is now experiencing some expansion of tourism</td>
</tr>
<tr>
<td>Ourossogui</td>
<td></td>
<td>Toucouleur, Peul</td>
<td>Substantial migration to Côte d’Ivoire, central Africa and France</td>
</tr>
<tr>
<td>Tambacounda</td>
<td>0.8</td>
<td>Mandinka, Soninke, Peul</td>
<td>Poor region; strong community-based management of HIV</td>
</tr>
</tbody>
</table>
The site selection was intended to be as representative of Senegal as possible, in that there are both rural and urban areas with ethnic and socioeconomic diversity and varying HIV prevalence.

In view of the pioneering nature of the present study (no earlier studies had been carried out on the subject), several qualitative and quantitative research techniques were used in order to increase data collection capacity and allow for triangulation of information obtained. A crucial component of the approach consisted of systematically comparing two categories of respondents:

- people living with HIV and people affected by HIV: i.e. adults living with HIV; children living with HIV; children orphaned by AIDS; and the parents or foster parents of such children.

- people not infected with, or affected by, HIV and parents of children not orphaned by AIDS.

At each research site, with the assistance of medical personnel, an epidemiological data sheet was compiled, listing anonymous data on adults and children living with HIV. The sheets contained data about the serological status and sociodemographic background of the families involved. Local medical staff were then trained to administer the household and individual questionnaires. The research team took care of questionnaires for control groups that were selected on comparable social and demographic profiles. Additional information was obtained through case studies and through an analysis of drawings made by children (4 to 12 years of age). The children were asked to draw their families, their dreams and what they would like to be in the future and then to comment on their drawings. They were selected with the collaboration of the medical doctors treating them and with the prior agreement of their parents or foster parents. The drawings were only discussed in the presence of medical staff known to the children.

<table>
<thead>
<tr>
<th>Instruments</th>
<th>Surveyed population</th>
<th>Cases</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epidemiological data sheet</td>
<td>Adults and children living with HIV</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>Child-centred medical data sheet</td>
<td>Children living with HIV (n=34)</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>Adult-centred medical data sheet</td>
<td>Adults living with HIV (n=100)</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>Household questionnaire</td>
<td>Adults living with HIV (n=100)</td>
<td>Adults not living with HIV (n=100)</td>
<td></td>
</tr>
<tr>
<td>Individual questionnaire on children (administered to parents)</td>
<td>Children not living with HIV (n=34)</td>
<td>Children living with HIV (n=34)</td>
<td></td>
</tr>
<tr>
<td>Children’s drawings</td>
<td>Children living with HIV (n=7)</td>
<td>Children not living and not affected by HIV (n=7)</td>
<td></td>
</tr>
<tr>
<td>Case studies</td>
<td>Adults living with HIV, or related to someone who had died of AIDS (n=10)</td>
<td></td>
<td>-</td>
</tr>
</tbody>
</table>
Finally, semi-structured interview guides were used to obtain information from key informants in ministries, international organizations and NGOs, and from people directly in contact with children and adults living with HIV and their families.

**Impact of HIV and AIDS**

**Impact at the national level**

At the national level, so far the epidemic has had no significant impact on demographic indicators or on the health or education sectors.

At the end of 2003, more than 90 per cent of the people living with HIV nationwide (low and high estimates 22,000 and 89,000 respectively) were aged between 15 and 49 years (UNAIDS 2004). In 1997, a study carried out at the main infectious diseases clinic in Dakar showed that 25 per cent of women infected with HIV were aged between 20 and 30 years, and 72 per cent between 30 and 40 (Sow et al. 1997). In the current study sample, 92 per cent of the HIV cases were between 30 and 40, with an average age of 38. Given the relatively low numbers compared to the total population of over 9 million, developments in key demographic indicators such as the structure of the population pyramid, life expectancy, or population growth cannot be attributed to the number of AIDS-related deaths. On the contrary, life expectancy increased from 1970 to 2000. Similar conclusions can be drawn with regard to the under-five mortality rate, which fell from 300 per 1,000 live births in 1960 to 147 per 1,000 in 1990 and then to 145 per 1,000 in 1999, despite a slight increase in recent years (chapter 10). The infant mortality rate also dropped from 173 per 1,000 in 1960 to 68 per 1,000 in 1999 (UNICEF 2000).

The nationwide impact on the health and education sectors has been negligible so far, and in contrast to countries such as Uganda, neither teachers nor health personnel are regarded as high-risk groups, so they are not included in regular epidemiological surveys.

**Impact at the household level**

At the household level, the social, human and physical impact on families affected by HIV is considerable and they have to adopt specific strategies in order to cope (chapter 7).

**Structure and dynamics of HIV-affected households**: An analysis of the medical records of those studied shows that, in most cases, HIV-infected children lived with a parent who had the same serological status. In fact,

- 96 per cent of infected children had at least one HIV-infected parent (father and/or mother);
• 74 per cent of infected children had at least one parent who died of AIDS (among these children, 59 per cent lost their father, 29 per cent their mother and 12 per cent both parents);

• 11 per cent had an HIV-infected brother or sister;

• 20 per cent of HIV-infected children had a family member who was currently in hospital or had been hospitalized that year.

The results of the adult-centred questionnaire reveal that typically more than one member of a household is infected with HIV.

Table 5. Presence of HIV infection within households

<table>
<thead>
<tr>
<th>People infected with or affected by HIV, in families with at least one HIV-infected person</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV-infected spouse</td>
<td>43</td>
</tr>
<tr>
<td>HIV-infected child</td>
<td>32</td>
</tr>
<tr>
<td>Women with at least one husband who died of AIDS</td>
<td>28</td>
</tr>
<tr>
<td>Men with at least one wife who died of AIDS</td>
<td>31</td>
</tr>
<tr>
<td>Families with at least one child orphaned by AIDS</td>
<td>22</td>
</tr>
</tbody>
</table>

Source: Adult-centred questionnaire.

However, the data presented have to be interpreted merely as indications about the presence of people infected with or affected by HIV living in the same household. The figures do not reflect the whole truth because the serological status of family members is not always revealed. When a man discovers that he is HIV-positive, he does not necessarily take the initiative to have his wife (or wives) and children tested, and according to health workers, when a woman discovers that she is HIV-positive, her husband often refuses to be screened.

The poor awareness about the existence of HIV cases within families is due to the fact that the subject of HIV and AIDS is still considered taboo. Very often, HIV-infected people strive hard to hide their condition from members of their families. In some cases, a communication gap is purposely created. The case of a migrant who returned home is illustrative:

*When I came back from Central Africa, I was admitted to Fann hospital, where I was told that I had tuberculosis and AIDS; when I came out of hospital, I talked about my tuberculosis to my wives, brothers and sisters, but I didn’t dare talk about the AIDS disease. I kept it secret for months. During that period, I kept silent when faced with embarrassing questions, and I considerably reduced sexual intercourse with my wives, arguing that my tuberculosis stopped me.*

While, in these circumstances, children are obviously not receiving the care they need from their parents, the extent to which the communication gap between parents
affects children’s lives is difficult to assess. But an analysis of children’s drawings reinforces the impression that the presence of HIV within a family, even though people will avoid talking about it, has an impact on the way in which the children reconstruct the image of their families and social environment. In a drawing by 10-year-old Momo who was infected with HIV but did not know it and whose mother was also infected, his uncle, aunt and cousins appear in the foreground, while his father and mother are only in the background in much less detail. His father had died of an HIV-related illness two years previously. Was he confused and so drew the living and the dead together, or did he put the family members whom he felt were different in the background? Unlike all the other children who pictured their families, Momo did not put himself in his drawing. Perhaps he could not find his place between the two groups. When he was asked to draw his house, like other children in HIV-infected families, Momo painted it in the form of a prison, with vertical and horizontal iron bars. Perhaps the prison represented the isolating effect of HIV or the burden it inflicts on those infected and affected by the virus.

Samba, a five-year-old boy, was another child who separated his family members according to whether or not they were infected by HIV. In his case, he put his uncle, brother and half-sister, who were not infected, in the background, and his HIV-positive mother and sister in front of them. But again, the family members who were HIV free were drawn in more detail. Samba was apparently anxious to keep his family intact, because he drew a circle around all the figures, emphasizing his mother who was the largest figure of the group.

In the context of Senegalese families, the mother’s position is central when it comes to taking domestic responsibilities arising from ill health; she keeps that role even if she is ill herself. When the mother is seriously ill, all the relatives, particularly her own sons and daughters, gather around her. When she has a medical condition such as HIV infection, rivalry between siblings born to different mothers can aggravate tensions. Thus the stigma of HIV may be felt even within the family unit. Moreover, the HIV-positive member may be blamed for being the cause of the ‘decline’ of the family’s status within the community.

Table 6. Percentage of families with members not part of the nuclear family unit

<table>
<thead>
<tr>
<th>People living in the family but not belonging to the nuclear family unit</th>
<th>Families with at least one HIV-infected person (%)</th>
<th>Families without any HIV-infected person (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brothers and sisters</td>
<td>29</td>
<td>41</td>
</tr>
<tr>
<td>Nephews and nieces</td>
<td>24</td>
<td>47</td>
</tr>
<tr>
<td>Sisters- and brothers-in-law</td>
<td>17</td>
<td>19</td>
</tr>
<tr>
<td>Grandchildren</td>
<td>11</td>
<td>21</td>
</tr>
<tr>
<td>Orphans</td>
<td>6</td>
<td>15</td>
</tr>
</tbody>
</table>

Source: Data from the adult-centred questionnaire.
Matrimonial status and instability of family units: Table 6 shows that households without any HIV-infected member are more likely to consist of extended families than those with at least one HIV-positive member.

The table confirms that it is normal practice for domestic units to include members of the extended family such as nephews and nieces or brothers and sisters of the head of household or his wife. It further shows the extent to which this practice has come under pressure when someone in the household is HIV-positive. As an interviewee commented:

*It is not advisable to entrust children to a poor or diseased person; this would add to that person’s troubles and would not provide the child with the ease and comfort he needs for his future.*

Table 7 shows the matrimonial status of households included in the survey.

**Table 7. Breakdown of matrimonial status of people living with HIV**

<table>
<thead>
<tr>
<th>Matrimonial status</th>
<th>Men living with HIV (%)</th>
<th>Women living with HIV (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>75.8</td>
<td>28.6</td>
</tr>
<tr>
<td>Single</td>
<td>21.2</td>
<td>22.4</td>
</tr>
<tr>
<td>Divorced</td>
<td>3.0</td>
<td>22.4</td>
</tr>
<tr>
<td>Widow</td>
<td></td>
<td>22.4</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>4.1</td>
</tr>
</tbody>
</table>

Source: Data from the adult-centred questionnaire.

It appears from the figures that a substantially higher percentage of women living with HIV are divorced or widowed and there are more married men than women who live with the condition. This can be attributed to the fact that when their partner dies, men remarry quite quickly or do not consider themselves as widowers when they are polygamists, because at least one of their wives is still alive.

In specific cultural contexts such as in northern Senegal – a region characterized by substantial outward migration – widows and divorcees used to be coveted for marriage. A migrant’s widow was, and to a certain extent still is, regarded as an excellent match because of her wealth and prestige. Divorced women also appeal to men because of the maturity it is assumed they have gained from previous marriages. However, it has been reported that widows of migrants now have increasing difficulties remarrying because their former husbands are suspected of having been HIV-positive.

**Table 8. Percentage of children moving into other households (1997–2001)**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Has had at least one child who lives with other relatives</td>
<td>10%</td>
<td>12%</td>
<td>12%</td>
<td>15%</td>
<td>16%</td>
</tr>
<tr>
<td>Has had at least one child who took the initiative to live with another relative</td>
<td>2%</td>
<td>5%</td>
<td>7%</td>
<td>9%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Source: Data from the adult-centred questionnaire.
The movements of children following the death of one of their parents or the disruption of a marriage are intimately related to complex social and cultural practices. When the father dies, for instance, according to tradition, the widow automatically marries his younger brother (a custom known as lévirat) and the children consequently move to another location. When the mother dies, her sister traditionally replaces her in the household (known as sororat), but informants affirmed that this practice is progressively declining in the areas covered by the survey. However, even without sororat, the widower typically seeks another wife without much delay, and as a result, the children of the deceased wife usually leave their father’s house. Their mother’s sisters may then bring them up. In other cases, it was noted that grandmothers or aunts substituted for the parents. The data reveal that children orphaned by AIDS who have lost both parents are in most cases adopted by their grandmothers, who are their closest relatives.

In the sampled households affected by HIV, a gradual reduction of the number of people involved in solidarity networks was observed. Responsibility for children orphaned by AIDS, for instance, appeared to rest upon a limited number of family members. Moreover, the most substantial support appeared to be provided by projects, associations or NGOs responding to AIDS. According to the survey data, 13 per cent of children with HIV benefited from some type of NGO assistance. The majority of those children live in Tambacounda, Saint-Louis and Dakar, where there is a dynamic environment of NGOs working in the area of HIV. The data further show that about 20 per cent of children infected with HIV (most of them living in Dakar, Kaolock and Tambacounda) have had at least one parent who benefited from an income-generating programme for people living with HIV.

In conclusion, after a parent’s death, children were found likely to have enormous difficulties accommodating themselves to their new family or matrimonial arrangements. It was often stressed by interviewees that the unstable situations described above make children feel marginal, undervalued and confronted with new and difficult challenges, a situation which, in turn, is aggravated by intra-household communication or affection deficits. In fact, the compassion expressed by others was said to be often only temporary.

Social networks: Analysis of the adult-centred questionnaire highlights many ways in which interpersonal relationships and social networks are adversely affected by the presence of HIV within families. While the death of a head of family usually results in the dispersal of family members (wives and children) who move into other, possibly separate, domestic units, the presence of HIV infection may cause disintegration or reorganization of the family unit.

A second feature that indicates the relative decline of social networks is the practice of sharing meals together. In traditional and rural families, meals are shared not only with household members but also with people who do not live in the same
compound. This practice is typically considered a sign of wealth or social prestige, and contributes significantly to the construction and maintenance of social networks. Yet, if the financial resources of a family are under pressure as a result of the presence of disease, the number of people who eat together may decrease. In addition to the stigma that is already faced by families living with HIV, the obligation to reduce the number of people with whom a meal is shared is likely to contribute to the relative social isolation of the family concerned and to a decline in its social prestige. In turn, this is likely to influence the support-base an affected family relies upon.

Table 9 shows that HIV-affected families, on average, share their different meals with fewer people than non-affected families.

<table>
<thead>
<tr>
<th>Meals</th>
<th>Families with at least one person with HIV</th>
<th>Families unaffected by HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breakfast</td>
<td>6.42</td>
<td>7.89</td>
</tr>
<tr>
<td>Lunch</td>
<td>6.89</td>
<td>7.34</td>
</tr>
<tr>
<td>Dinner</td>
<td>8.02</td>
<td>8.11</td>
</tr>
</tbody>
</table>

Source: Data from the adult-centred questionnaire.

People with whom meals are shared, or who live in the same compound, or with whom a family type of relationship exists, form the core group of the solidarity network that provides moral support, material assistance and health care to people who live with a disease. The brother of a migrant who died of an HIV-related illness illustrates this:

When AIDS laid him low, it was his roommates with whom he had shared meals who helped him return to Senegal. When he came home, his wife and elder brother took him to a series of hospitals, stayed with him until he died, caring for him and endeavouring to find money and traditional medical healers or marabouts who provided talismans and gris-gris.

Wives are often accompanied in their efforts by other women (such as sisters, cousins or close friends) or by their own daughters. Daughters, irrespective of their age, are involved in tasks such as bringing meals to the patient and carrying out domestic activities that would typically have been carried out by their mothers (cooking meals, taking care of children, cleaning the house, etc.). In this way, the father’s illness results in an increase of stress for young girls, and a possible cause of school failure or dropout. When the mother herself is ill, the situation worsens because her daughters have to take care of her. Finally, in situations where the mother cares for an ill child, the burden of her domestic chores is borne by her daughters or by other girls who live in the same compound.
The results of the survey show that just after the revelation of HIV infection or the occurrence of AIDS symptoms, families benefit substantially from assistance provided by relatives, friends or neighbours, but that resource mobilization consistently declines over time. Moral support is also apparently difficult to maintain. At the onset of illness, people show their sympathy for, and provide assistance to, the patient, but if that support needs to be kept up for an unlimited length of time, the solidarity network soon runs out of steam.

Paradoxically, when they have health problems, families that are not affected by HIV receive more assistance to meet additional expenses than do families that are affected by HIV. This assistance is likely to be provided by parents, relatives, neighbours and friends, whereas patients with HIV-related illness rely much more on health structures, organizations that assist people living with HIV, marabouts or the inner circle of family members. The gap widens when data about women are examined.

However, even though solidarity networks tend to tighten as HIV continues to place more and more of a burden on families, when the patient dies, resource mobilization starts anew, with the widening of the circle of community members involved in providing assistance for the funeral. These generally gather many people, as is illustrated by the following anecdote:

*We, my brothers and I, wanted the funeral to be as simple as possible. Our dead relative and his intimate friends and family had already suffered much from the disease and its attendant problems. But because of the crowd of people who came for condolences, we had to slaughter a bull and many relatives and visitors stayed in the house for more than 10 days.*

As well as impoverishing families, funerals disturb children’s lives. The children are the first to have to sleep on the floor and leave their beds to visitors or be sent to neighbouring homes for long sleepless nights. Few people take the trouble to look after children on such occasions, and they are overwhelmed with domestic duties, which may affect their school results.

**Impact on human capital**

The impact of HIV on human resources has been analysed through indicators related to health care, education and nutrition.

**Health care:** Analysis of the impact of HIV on health care was based on examination of medical expenses: consultations, biomedical screening and hospital admissions (see also chapter 10). As might be expected, the number of people with HIV who had been to a health centre during the three months preceding the survey was higher than the number of non-infected people.
Table 10. HIV and health-care indicators

<table>
<thead>
<tr>
<th>Health care indicators</th>
<th>Adults with HIV</th>
<th>Adults without HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one consultation in the last 3 or 6 months</td>
<td>89%</td>
<td>69%</td>
</tr>
<tr>
<td>Average number of consultations in the last 3 months</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Average consultation costs in the last 3 months (in CFA francs)</td>
<td>8,085</td>
<td>3,458</td>
</tr>
</tbody>
</table>

Source: Data from adult-centred questionnaire.

The number of adults with HIV who had ever been admitted to a hospital was also greater: 32 per cent, as against 10 per cent for non-infected adults. On average, adults infected with HIV paid almost twice as much for consultations as did those without, although in localities like Saint-Louis, HIV-infected patients do not pay for consultations in public hospitals. Those living with HIV also paid more for medicines than their uninfected counterparts. Children’s health care expenses are traditionally the father’s responsibility, but on a day-to-day basis it is usually the mother who endeavours to find the necessary money, as she takes immediate care of the patient.

There was no significant difference in the percentage of people who had consulted a marabout or a traditional healer over the three months preceding the survey. Yet, from the analyses of expenses related to these visits, it appears that people with HIV spent significantly larger amounts. The number of people with HIV who were treated by a traditional healer or a marabout at home was also greater, and when they had to travel for their consultations, their expenses were considerably higher.

Table 11. HIV and consultations with marabouts or traditional healers

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Adults with HIV</th>
<th>Adults without HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consulted a marabout or a healer in the last 3 months</td>
<td>42.5%</td>
<td>45.5%</td>
</tr>
<tr>
<td>Average consultation costs (in CFA francs)</td>
<td>23,713</td>
<td>3,304</td>
</tr>
<tr>
<td>Average for other expenses (purchase of drugs or sacrifices; in CFA francs)</td>
<td>30,880</td>
<td>8,511</td>
</tr>
<tr>
<td>Average amount of gifts</td>
<td>23,713</td>
<td>3,304</td>
</tr>
<tr>
<td>Provided in-house lodging to a marabout or a healer</td>
<td>14%</td>
<td>4%</td>
</tr>
<tr>
<td>Average amount of money spent on transport to visit a healer or a marabout (in CFA francs)</td>
<td>6,309</td>
<td>2,595</td>
</tr>
</tbody>
</table>

Source: Data from adult-centred questionnaire.
The following extract from a case study from Saint-Louis throws light on how these expenses mount up:

_The first marabout my brother consulted lived in Ndioum. As he didn’t want his wife, who was with him, to know that he had HIV, he didn’t tell the marabout that he was HIV-positive but only explained that he was suffering from tuberculosis. The marabout asked for CFA francs 40,000 and promised he would recover. But my brother only gave him CFA francs 20,000 and said he would give the other half after the three-month treatment. The three months elapsed without any improvement. In October 1999, my brother heard about another marabout and went to see him. The latter told him that he was the victim of an evil spirit and that he should act promptly if he wanted to stay alive. He asked for CFA francs 4,875, a white ram, a white cock, 25 red kola nuts, 25 white kola nuts and 25 candles._

When people infected with HIV or members of their families talk to marabouts or healers, they never mention the name of the virus, but talk about another illness with similar symptoms. As a marabout from Ourossogui said:

_We do not cure AIDS because it is incurable and the patient inevitably has to die… AIDS patients are people who committed deadly sins. However, we do cure a disease that has infected migrants who have been in Côte d’Ivoire, Gabon and Zambia. This disease is called Jokao or Ñaw funange. Its symptoms are progressive loss of weight, diarrhoea, vomiting, hot flushes, fever and often itchiness or tumours on the back; we are the only ones who can heal that disease, no hospital can._

**Education:** The survey results show that 40 per cent of the children with HIV were of school age, and that of these, 89 per cent were currently attending formal education at public or private schools, with the remainder enrolled in Koranic schools. According to social workers interviewed, Koranic schools are generally considered to be substitutes for public education for children infected with HIV. The social workers suggested that parents hesitate to send their children to public schools because they think they will soon be obliged to drop out, or will not be able to find a remunerative job afterwards. Attending a Koranic school is seen as a way of getting closer to God. In addition to negatively affecting public school enrolment, HIV appeared, not surprisingly, to have an impact on school results. Children frequently miss classes and, as a consequence, tend to repeat grades. Of the children included in the survey, many were still at primary level even though most of them were over the age of 12.

The survey revealed that 6 per cent of the adults living with HIV said that at least one of their children had been dismissed from school during the school year 1999–2000. According to these parents, in addition to the children frequently missing classes (because of their extra involvement in domestic duties), the dismissals and poor school results were due to their failure to pay sufficient attention to their
children’s education and to difficulties with paying school registration fees or buying school stationery.

Table 12. Impact of parents’ HIV infection on children’s school results

<table>
<thead>
<tr>
<th>Type of difficulty</th>
<th>95–97%</th>
<th>97–98%</th>
<th>98–99%</th>
<th>99–00%</th>
<th>00–01%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child had to miss classes</td>
<td>1.2</td>
<td>1.2</td>
<td>3.7</td>
<td>4.9</td>
<td>4.9</td>
</tr>
<tr>
<td>Parents had difficulty buying school stationery</td>
<td>4.9</td>
<td>12.2</td>
<td>12.2</td>
<td>13.4</td>
<td>13.4</td>
</tr>
<tr>
<td>Parents had difficulty paying school enrolment fees</td>
<td>3.7</td>
<td>8.5</td>
<td>8.5</td>
<td>9.8</td>
<td>7.3</td>
</tr>
<tr>
<td>Parents stopped paying private tuition fees</td>
<td>2.4</td>
<td>3.7</td>
<td>3.7</td>
<td>3.7</td>
<td>6.1</td>
</tr>
<tr>
<td>Parents had difficulty paying transport to school</td>
<td>1.2</td>
<td>2.4</td>
<td>2.4</td>
<td>3.7</td>
<td>3.7</td>
</tr>
</tbody>
</table>

Source: Data from the child-centred questionnaire.

**Nutrition:** Analysis of the impact of HIV on the household nutrition situation shows that the main changes occur in the variety and quantity of food available, and the difficulty of paying for it.

Certain practices are considered to be poor in terms of nutrition and to reflect a lack of financial resources. This is the case, for instance, when part of the lunch is kept and then heated up for dinner. Traditionally, meals served for lunch and dinner are qualitatively different (rice for lunch and millet or another dish eaten with bread at night). The practice of reducing food diversity appeared to be more frequent among HIV-affected households, for whom the percentage increased from 15 per cent in 1996 to 32 per cent in 2001. Over the same period, only a very low percentage of non-affected households changed their food habits.

The practice of serving part of the lunch at night not only represents restricted variety in the diet and a decline in food expenditure, it also suggests that the quantity of food eaten by adults or older children decreases, as very often the remains of midday meals are kept for younger children. The percentage of people who acknowledged that the quantity of food served had decreased was substantially higher among HIV-affected households: it rose from 11 per cent in 1996 to 32 per cent in 2000–2001, while the percentage remained low and stable for non-affected households. A quantitative reduction in nutrition often means that the family breakfast is eliminated or reduced to a minimum (and might be reserved for the youngest children), that dinner is not served every day, or that sometimes lunch is not cooked or is served very late, because the mother had to find help to purchase the food.
Children are likely to suffer from these coping strategies that result in reduced quality and quantity of nutrition at the household level. For instance, the percentage of HIV-affected adults who stated that their children did not have breakfast every day rose from 15 per cent to 20 per cent over the 1996–2001 period, while fewer than 2.2 per cent of the non-affected people reported such a problem.

The survey results further illustrate that HIV-affected households have difficulty meeting daily food expenses. Over the period 2002–2001, almost one third of respondents in this category declared that at least occasionally the purchase of food items was problematic. It was difficult to get a detailed and systematic overview of household budgets, but the data indicate that the average level of household expenditure is noticeably lower in families with at least one HIV-infected person, although both types of families included in the survey were of comparable size and were headed by adults with similar professional activities. The most significant disparities were in foodstuffs bought on a daily basis. Moreover, the majority of the indicators reveal downward trends over the period, which can be interpreted as a gradual worsening of living conditions for families affected by HIV.

**Physical capital:** The impact of HIV on the physical capital of families concerned was examined by analysing the role of domestic savings and the availability of material property. The survey results reveal that domestic savings are used to meet health care expenses. In rural areas, domestic savings are typically in the form of livestock. When cash is needed in an emergency to purchase food or cover medical expenses, livestock is only sold if no other options are available. Livestock, especially cattle, are crucially important for the social prestige and livelihood of their owners, so they are only sold as a last resort. When HIV-affected households occasionally did have to sell livestock in order to raise necessary cash, it was usually sheep and goats rather than cattle that they disposed of. In urban areas, a
significant number of HIV-affected people had to resort to borrowing money or using bank savings.

Another crucial indicator of the impact on physical capital is access to basic social services such as water and electricity, which have a direct impact on the household’s living conditions and on the environment in which the children grow up.

The questionnaire data indicate an increase among HIV-affected households in the number of power cuts due to unpaid electricity bills. While 4.5 per cent of this group had power cuts for non-payment of bills in 1996–1997, the figure had risen to 12.6 per cent in 1999–2000 and 11 per cent in 2000–2001. Over the same period, the percentage among non-affected households rose from zero to 5.5 per cent. Power cuts are seen as one of the more visible indicators of a decline in a family’s financial status and are likely to affect children’s welfare, particularly as regards their education. The children are ashamed in front of their school mates, and have difficulty studying at home by candlelight or even fail to do their homework altogether.

Unpaid water bills lead to similar problems. Figure 3 shows that for HIV-affected households, water supply cuts became more and more frequent between 1998 and 2000 when they were reported by almost 14 per cent. For non-affected households, the percentage ranges between 3 per cent and 5 per cent. In addition to potential health problems for children, interruptions in the water supply tend to give more work to children, particularly girls, as they are usually in charge of fetching water from neighbouring houses or public water sources.

**Figure 2. Percentage of people who had power cuts as a result of non-payment of electricity bills**

<table>
<thead>
<tr>
<th>Year</th>
<th>Cas (%)</th>
<th>Témoin (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>96-97</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>97-98</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>98-99</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>99-00</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>00-01</td>
<td>10</td>
<td>8</td>
</tr>
</tbody>
</table>

Key: Cas = people with HIV; Témoin (control subjects): people without HIV.
Source: Data from the adult-centred questionnaire.
**Figure 3. Percentage of people who reported having water supply cuts due to non-payment of bills**

<table>
<thead>
<tr>
<th>Year</th>
<th>Cas</th>
<th>Temoin</th>
</tr>
</thead>
<tbody>
<tr>
<td>96-97</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>97-98</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>98-99</td>
<td>10%</td>
<td>10%</td>
</tr>
<tr>
<td>99-00</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>00-01</td>
<td>15%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Key: Cas = People with HIV; Témoin (control subjects): People without HIV.
Source: Data from the adult-centred questionnaire.

**Impacts at the individual level**

HIV has an important psychological impact on infected people. This is illustrated by several of the indicators used in the questionnaire, which, among other things, reveal that more than half the HIV-positive adults acknowledged frequently feeling upset. For 60 per cent of this group, this feeling was usually accompanied by a sense of depression, which together with the physical symptoms, led more than half the patients to stay in bed for hours on end.

Although HIV-infected people frequently gave the impression that they had been ruined and lost much of their property because of the virus, comparatively few divorces linked to HIV were recorded. It seems that divorce under such circumstances would be seen as a transgression of the moral principles underlying marriage, which is considered to be the fulfilment of God’s will.

The general psychological mood of many people living with HIV is summed up by the following passage taken from a life-history recounted in Ourossogui:

*When I was told I was HIV-positive, I felt very sad and depressed. I often stayed in bed and rarely went outdoors for my usual errands; I thought I was good for nothing and was overwhelmed by feelings of failure and guilt. I did not work because I entrusted my little shop to one of my brothers who was managing it well.*

Similar cases confirm that the emotional shock of the discovery of being HIV-positive can lead to instability in one’s professional and social activities.
<table>
<thead>
<tr>
<th>Impact of HIV</th>
<th>People living with HIV (%)</th>
<th>People not living with HIV (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Often feels upset</td>
<td>51.2</td>
<td>12.1</td>
</tr>
<tr>
<td>Is often in a melancholy mood</td>
<td>58.5</td>
<td>19.8</td>
</tr>
<tr>
<td>Stays in bed for hours</td>
<td>46.3</td>
<td>16.5</td>
</tr>
<tr>
<td>Is broke</td>
<td>47.6</td>
<td>19.8</td>
</tr>
<tr>
<td>Lost his/her property</td>
<td>40.2</td>
<td>11.8</td>
</tr>
<tr>
<td>Decided to stop having children</td>
<td>29.3</td>
<td>2.2</td>
</tr>
<tr>
<td>Relatives and friends avoid meeting him/her</td>
<td>14.6</td>
<td>1.1</td>
</tr>
<tr>
<td>Stopped entertaining himself/herself</td>
<td>32.9</td>
<td>11</td>
</tr>
<tr>
<td>Travelled for treatment</td>
<td>18.3</td>
<td>3.3</td>
</tr>
<tr>
<td>Was divorced</td>
<td>4.9</td>
<td>2.2</td>
</tr>
<tr>
<td>Was abandoned by spouse</td>
<td>4.9</td>
<td>3.3</td>
</tr>
</tbody>
</table>

Source: Data from the adult-centred questionnaire.

Children, especially those living with HIV themselves, can be highly affected by adults’ social and emotional instability. In the drawing of an HIV-infected boy, the HIV-positive father occupies a tiny space in the background. According to psychologists, this means that while physically present, the father tends to disappear from the child’s imagination. They explain that children who live in similar situations are often faced with problems of identifying with people who live in their immediate environment.

Occasionally, children sense the fact they live with HIV, even if nobody told them so. Samba, who did not know that he was living with HIV, drew himself without his arms. It was as if he felt he was maimed. It probably did not mean that Samba was unable to draw his limbs accurately or that he had accidentally forgotten them. He just wanted to express the idea that he had something missing.

The feeling of discomfort experienced by HIV-infected children is highlighted in the replies to the child-centred questionnaire. In 35 per cent of cases, parents of children infected with HIV realized that their children had been rejected by many of their friends. They therefore played less. They were also frustrated by the lack of other forms of socialization that would have allowed them to escape the family environment momentarily. None of the parents of children living without HIV mentioned such problems.
On the other hand, no systematic discrimination of children was observed in schools or other locations at which children socialize. An informant from Tambacounda explained:

_In most cases, neither the teacher nor the students know that there is an HIV-positive pupil in the classroom. When the pupil misses classes for health reasons, they just say he/she is sickly, without envisaging the possibility of HIV. If ever the teacher knows that one of his pupils is HIV-positive, he tries hard to keep it secret._

Often, the fact of not revealing the HIV status in school is related to it being hidden at home. Sometimes family members are the last to know that one of their relatives is HIV-positive. Thus, conflicts may arise from strategies developed within families to conceal the disease, and these in turn are likely to have considerable emotional impact.

**Conclusions**

Analysis of a variety of indicators related to the periods before and after the onset of AIDS in Senegal (mid-1980s) did not permit an assessment of its nationwide impact in general, or the sectors of health, education, demography and economy in particular. This can undoubtedly be attributed to the relatively low and stable rate of HIV prevalence and to the low number of deaths from HIV-related illnesses. These favourable figures are generally attributed to a complex set of social and behavioural factors, complemented by a successful policy to fight against the spread of the virus. The main features of this policy consist of a timely response, an eagerness to anticipate new developments, the strategic involvement of religious and political leaders, effective STI control programmes and strong responses at the community level.

However, the study clearly identified the impact of HIV at the family and individual levels. At the family level, it was observed that the serological status of individual members is rarely known, presumably because of the taboo that still exists.

---

**Table 14. Impact of HIV on child socialization situations**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Children living with HIV (%)</th>
<th>Children not living with HIV (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stopped playing</td>
<td>33</td>
<td>18</td>
</tr>
<tr>
<td>Often in bed</td>
<td>50</td>
<td>36</td>
</tr>
<tr>
<td>Rejected by friends</td>
<td>35</td>
<td>-</td>
</tr>
<tr>
<td>Lost appetite</td>
<td>60</td>
<td>29</td>
</tr>
<tr>
<td>No longer goes on holidays</td>
<td>65</td>
<td>14</td>
</tr>
</tbody>
</table>

Source: Data from the child-centred questionnaire.
People who are HIV-positive may face stigma both at the community level and within their families – particularly in the case of a polygamous family.

For HIV-infected families, health care expenses constitute a heavy burden, especially those related to the treatment of opportunistic infections and consultations with marabouts and traditional healers. These expenditures contribute to unstable and progressively deteriorating living conditions for children, particularly girls. The presence of HIV was found to lead to changes in the family structure, matrimonial problems and the gradual decline of social networks, thus adversely affecting children’s growth and development still further. Moreover, discovery of HIV-positive status appeared to have a strong impact on the self-esteem and emotional stability of individual adults and children.

The results of this study suggest that, if the programmes which aim to reduce the presence and impact of HIV were to be strengthened, they should include specific components focusing on children and families that are vulnerable to HIV infection, notably in the field of communication on HIV and AIDS. These programmes should not be limited to prevention efforts but should also cover care for the infected.

References and Bibliography


Notes

1 Epidemiological data for 2002 show that HIV prevalence remained relatively low and stable (Bulletin Séro-Epidémiologique du VIH N°10, July 2003, Ministry of Health). HIV infection of pregnant women was found to be 1.2 per cent on average, with regional figures varying from 0.2 per cent (Saint-Louis) to 2.9 per cent (Kolda). HIV prevalence among sex workers varied between 5.1 per cent (Mbour) and 28.5 per cent (Ziguinchor).

2 The 2002–2006 strategic plan for the response to AIDS, elaborated at the time this research was undertaken, confirms this integrated approach. Whereas the Health Ministry used to be the coordinating body, the newly established National Council on the Fight against Aids (CNLS) is attached to the Prime Minister’s Office. Focal points have been appointed in several Ministries and there is strong involvement of civil society organizations. In addition, the 2002–2006 strategic plan provides for the strengthening of institutional mechanisms at decentralized level.
Chapter 4
The Impact of the AIDS Epidemic on South Africa’s Children
Jeff Gow and Chris Desmond

with Peter Badcock-Walters, Frikkie Booysen, Rob Dorrington, Deborah Ewing, Sonja Giese, Leigh Johnson, Neil McKerrow, Shirin Motala, Rose Smart and Judith Streak

Introduction
This chapter highlights the many impacts that HIV and AIDS impose upon South Africa’s children. Efforts under way to alleviate these impacts are critically examined. Alternative policies and programmes that could potentially better alleviate the impacts are also discussed.

Initially, the nature of the epidemic and its likely impacts upon the populations of adults and children are examined. The chapter then goes on to discuss the impact of increased illness and death from AIDS on the health, welfare and education of children. Many children are already living in poverty. These areas are examined in terms of household level economic strain and the capacity of the community systems designed to provide services to children to meet these extra demands. Attention is then given to interventions that currently exist in terms of prevention and mitigation. Family, community and, in particular, state responses are outlined and critiqued. This information is used to identify key concerns and areas for action.

Impacts
Population
South Africa has a young population. Out of a total of 44.8 million, 17.3 million, or 39 per cent of the population, were under 18 in 2001. The AIDS epidemic has had many negative implications for South African society, which stem from the illness and eventual death resulting from HIV and AIDS. The identification of impacts needs, therefore, to be placed in the context of the scale of illness and death.
The following section examines the path that the epidemic is expected to follow and the implications this has for illness, death and the population structure.

**Modelling results:** The projections in this section are based on the ASSA2000 model developed by the Actuarial Society of South Africa. They are reported as at 2002 in Dorrington, Bradshaw and Budlander (2002).

Figure 1 shows the significant impact AIDS is having on the mortality of the South African population. The past trend of falling IMR (infant mortality rate) has been halted and IMR is likely to remain above 50 per 1,000 for the next 10 years. Most paediatric AIDS mortality is likely to occur after the first year of life and there is not only a reversal of a previous downward trend but a significant increase (around 50 per cent over the next 10 years) in the childhood mortality rates (newborn child dying before reaching age five). In 2004 it was estimated to be at its highest level in almost 20 years. But even more startling than this is the impact on adult mortality (as measured by the 45q15, the probability of a fifteen-year-old dying before reaching age 60). This rate is expected to increase by some 150 per cent by 2010, from around 30 per cent to around 80 per cent, implying that without behavioural change, half of all adults can be expected to contract the virus during their lifetimes.

**Figure 1. Mortality rates per 1,000 live births**

Figure 2 shows that these effects have the consequence of reducing life expectancy at birth in South Africa from over 60 years in the mid-1990s to slightly above 40 years by 2010 (see also table 1).
Figure 3 shows that the number of AIDS deaths is expected to exceed the number of deaths by all other causes within the next three years. Included in this figure are the numbers of new infections, showing that although these have already peaked, the number of deaths is only expected to peak in 2010.

Figure 2. Impact on life expectancy at birth

Figure 3. Comparison of the number of new HIV infections with the number of deaths
Figure 4 shows that the population growth rate is expected to fall to zero over the next few years and that the South African population is unlikely to exceed 50 million. The number of children under the age of 15 whose mothers have died of AIDS is expected to rise from some 878,000 currently to around 1.4 million by 2010.

It is expected that the number of infected people in the population will peak at between 7 million and 8 million, in contrast with the current estimated number infected of 5.3 million, while the country will have to cater for approximately 1 million people living with HIV. A total of between 5 million and 6 million people will probably have died of AIDS by 2010.

Figure 5. Provincial childhood mortality rates
Figure 5 illustrates the impact of the epidemic on childhood mortality (per 1,000) in the nine provinces. In the most severely affected province, KwaZulu-Natal, the child mortality rate is expected to exceed 140 per 1,000, more than double the rate in the late 1980s. Even in the Western Cape, which has the lowest overall prevalence, HIV will reverse the downward trend in child mortality. Adult mortality rates have already increased in all the provinces and this rise is set to continue.

HIV and AIDS are already affecting the size and structure of South Africa’s population and the impacts on the population are only in their infancy. High levels of child and adult death will have many follow-on impacts. Table 1 incorporates some health, education and welfare indicators with recent past measures.

### Table 1. Health, education and welfare measures (1985–2000)

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Life expectancy at birth – without AIDS</td>
<td>58</td>
<td>59</td>
<td>63</td>
<td>66</td>
</tr>
<tr>
<td>Life expectancy at birth – with AIDS</td>
<td>58</td>
<td>59</td>
<td>55</td>
<td>47</td>
</tr>
<tr>
<td>Infant mortality rate (measured – DHS) b</td>
<td>0.062</td>
<td>0.052</td>
<td>0.046</td>
<td>0.058</td>
</tr>
<tr>
<td>Child mortality rate – without AIDS (estimated ASSA) b</td>
<td>0.079</td>
<td>0.071</td>
<td>0.062</td>
<td>0.057</td>
</tr>
<tr>
<td>Child mortality rate – with AIDS (measured – DHS) b</td>
<td>0.070</td>
<td>0.052</td>
<td>0.058</td>
<td>0.091</td>
</tr>
<tr>
<td>DPT3 immunization coverage</td>
<td>75%</td>
<td>72%</td>
<td>72%</td>
<td>76%</td>
</tr>
<tr>
<td>Measles immunization coverage</td>
<td>70%</td>
<td>79%</td>
<td>76%</td>
<td>82%</td>
</tr>
<tr>
<td>Antenatal care</td>
<td>–</td>
<td>–</td>
<td>89%</td>
<td>94%</td>
</tr>
<tr>
<td>Delivery attendance</td>
<td>–</td>
<td>–</td>
<td>82%</td>
<td>84%</td>
</tr>
</tbody>
</table>

**Education c**

| Primary school female gross enrolment | 114 | 120 | 130 | 103 |
| Primary school male gross enrolment | 116 | 123 | 135 | 109 |
| Secondary school female gross enrolment | 52  | 80  | 103 |
| Secondary school male gross enrolment | 55  | 69  | 88  |
| Pupil–teacher ratio                  | 34:1| 33:1| 34:1| 33:1|

**Social welfare a**

| Maternal or double orphan children | –   | –   | 3.6%| 5.2%|
| Maternal or double orphans from AIDS | –   | –   | 36%| 61%|

Sources: a) Health and social welfare data supplied by Professor Fabio Zagonari; b) 2000 figures from Dorrington, Bradshaw and Budlander (2002); c) All education data are from UNESCO Institute for Statistics.
Social epidemiology

**Bio-medical factors:** The most significant bio-medical factor driving the epidemic in South Africa is the high prevalence of sexually transmitted infections (STIs). Genital sores and ulcers caused by these STIs greatly increase the risk of HIV transmission, and there is thus a significant correlation between levels of STI and HIV prevalence.

Levels of STI treatment are low for a number of reasons. Firstly, many STIs (particularly those affecting women) are asymptomatic, and even when symptoms occur, they may not be recognized as being due to infection. A second problem is that even when symptoms occur, individuals will often not seek treatment, either because treatment is inaccessible or because the infection is not regarded as being serious. To aggravate the situation further, treatment is often ineffective.

The relationship between HIV prevalence and STI prevalence is demonstrated in figure 6. HIV prevalence levels among pregnant women, estimated from the 1998 antenatal clinic survey (Department of Health 1999a), are compared with percentages of men reporting having had painful urination, penile discharge or genital sores in the last three months from the South Africa Demographic and Health Survey (Department of Health 1999b), in each of the nine provinces. With the exception of Gauteng and the Northwest, there is a pattern of high HIV prevalence in provinces with high STI prevalence, and lower HIV prevalence in provinces with low STI prevalence.

**Knowledge and belief about HIV and STIs:** Although a large number of public HIV awareness and education programmes have been launched in South Africa, there remains a significant proportion of the population that – due to illiteracy, geographical isolation or misinformation – is still ignorant of the basic facts of HIV.

Figure 6: Comparison of STI and HIV prevalence levels (1998)

Source: Department of Health 1999a and 1999b.
Sexual abuse and the status of women: In 1998 South Africa had the highest per capita rate of reported rape in the world (115.6 for every 100,000 of the population), and – on the common but highly debatable assumption that only one in every 20 rape cases are reported – close to 1 million acts of rape occur in South Africa every year (Rape Crisis Cape Town 2001). Marital rape is particularly under-reported, with many relationships being characterized by violence and sexual abuse. Vundule et al. (2001) found, in a study of black teenagers attending antenatal clinics in Cape Town, that 72 per cent of girls reported having been forced to have sex at some stage, and 11 per cent reported having been raped. The South African National Youth Survey (Kaiser Family Foundation 2001) also found that 39 per cent of sexually experienced girls had been forced to have sex, and 33 per cent reported being afraid of saying no to sex. In many cases, therefore, women have limited control over their sexual activity, and are thus more vulnerable to HIV infection.

Migration patterns: South Africa has experienced high levels of political and economic migration in recent decades, both between its provinces and between itself and its neighbouring states. Migration increases the extent of sexual networking, and thus facilitates the swift spread of the HIV epidemic. This is demonstrated in a study of a rural community in KwaZulu-Natal: people who had recently changed place of residence were three times more likely to be HIV-positive than those who had not (Abdool Karim et al. 1992). It is therefore a concern that, in some rural areas, rates of migrant employment for those between the ages of 19 and 49 are as high as 60 per cent of males and a third of females (Lurie et al. 1997).

Health impacts

Perhaps the most startling evidence of the impact is the effect that the HIV pandemic is expected to have on child health indicators, the morbidity and mortality of women and young adults, and the number of children who will be orphaned. Increased morbidity and mortality in young adults reduces the pool of caregivers and breadwinners, leaving an increasing number of children in conditions of poverty and neglect. The ‘orphan epidemic’ in South Africa is a crisis in its own right with 3 million orphans expected within the next 10 years. Children orphaned by AIDS are arguably the most vulnerable children in our society, struggling not only to survive, but also to do so within the context of open discrimination.

The impact of HIV on child health is being reflected in a reversal of the gains achieved in improving child health indicators over the 1980s and first half of the 1990s. Trends in improvement in infant mortality obtained through successful child survival programmes over the past 15 years have been reversed, and predictions are that if the transmission of HIV from mother to child is not prevented, child mortality rates will increase to over 100 per 1,000. Few events impact as severely on the health and well-being of a child as the death of his or her mother. The
maternal mortality rate in South Africa is 150 per 100,000 live births. In 1999, non-pregnancy-related infection was the leading cause of maternal mortality and 30 per cent of these deaths were AIDS-related. In most provinces, AIDS has emerged as the major contributory cause of maternal deaths. The implications for the health of children will be widespread, but some will be particularly vulnerable.

Three groups of children are particularly vulnerable:
1) Children living in households where one or more family members is HIV-positive.
2) Children orphaned by AIDS.
3) Children who are HIV-positive.

Child health and well-being in infected households

Poor health among children living in HIV-infected families is common. This is believed to be a consequence of HIV itself (in the case of MTCT), increased exposure to opportunistic infections, disease-related poverty and psychosocial factors that impact on caregiving practices and child well-being (Piwoz and Preble 2000). Children living in households with HIV-infected persons are more exposed to opportunistic infections, such as TB and pneumonia. With caregivers sporadically sick or absent, the child is less likely to get the medical attention he or she needs and more likely to have repeat infections.

Children orphaned by AIDS: South Africa already has 500,000 maternal orphans caused by AIDS, yet the ‘orphan epidemic’ is still in its infancy and over the next few years is expected to grow to devastating proportions. In most parts of the industrialized world, no more than 1 per cent of the child population is orphaned. In low- and middle-income countries this figure was around 2.5 per cent before the AIDS pandemic (Loening-Voysey and Wilson 2001). If one combines all other causes of maternal death with the AIDS pandemic, 11 per cent of children under the age of 15 years in South Africa are orphans and this figure is expected to rise to almost 17 per cent by 2010 (SA National Council for Child and Family Welfare 1999). By 2015, children orphaned by AIDS will constitute between 9 per cent and 12 per cent of South Africa’s total population.

Children infected with HIV: As of end-2003 there were an estimated 230,000 children 0–14 years old who were infected with HIV (UNAIDS 2004). The majority acquire HIV from their infected mothers during pregnancy, at the time of delivery, or after birth through breastfeeding; 60 per cent of these children will not live beyond their fifth birthday, but 40 per cent of them will, and the majority of these children will join the 60 to 70 per cent of children in South Africa who live in conditions of extreme poverty.
Fifteen to 18-year-olds fall within the age category most vulnerable to HIV infection through sexual contact. Within this group, girls are particularly vulnerable to infection. Physiological, cultural and social factors contribute to their vulnerability and girls between the ages of 5 and 14 years are over eight times more likely to be infected through sexual abuse than their male counterparts (Shell 2000). In sub-Saharan Africa, the rate of HIV infection in teenage girls is five times higher than the rate of infection in teenage boys (Mpanju-Shumbusho 2001). The reason for the lower differential between teenage boys and girls is that the male/female difference in risk is not as marked for older teenagers as it is for younger children.

**Education impacts**

The process of education and learning is the key to social, cultural and political participation, personal and community economic empowerment and national development. Its output is the human capital that constitutes the nation’s primary wealth and potential for growth.

One third of all HIV-positive persons in South Africa were infected during their school years, while a further third were infected within two years of leaving school. This confirms schools as a high-risk environment.

In 2000, 12 million students were enrolled in South African public schools. However, it is estimated that less than a quarter of children five to seven years of age were enrolled in early childhood education programmes. Many children living in poverty are denied access to basic education because they cannot afford to pay school fees or purchase school uniforms. Over 1.2 million school-age children do not attend school. The HIV epidemic is exacerbating these trends.

**The impact of HIV in the home and on education:** The incidence of HIV in the home can be expected to further reduce access to education. This will occur due to increased economic hardship, family care and other household or agrarian duties, the need to find employment, declining health due to deteriorating nutrition and other opportunistic infections, and the effects of personal trauma associated with grief, stress and added responsibility. The child in an affected household, with an infected parent to consider and even care for, will be exposed to a variety of impacts that together may reduce or even preclude access to schooling, either temporarily or permanently.

**Gender inequity and access:** South Africa has had, and to an extent continues to have, a unique level of gender equity in its schooling system, relative to its sub-Saharan neighbours. One obvious implication of the epidemic is that girls will be more affected than boys, so the balance will be upset. There are a number of reasons for this, including the fact that, in the event of economic hardship and deprivation, girls are more likely to be withdrawn from school than boys, and more likely to be held back to provide care both for the infected party and for siblings.
Girls are also more likely than boys to become the victims of sexual exploitation and may be driven to this course as a means of personal survival and household support. There is also likely to be a decline in the number of girls matriculating and a consequent drop in the gross number of matriculants.

**Welfare impacts**

The impacts on health and education are significant; there are, however, many other ways in which HIV will affect children. Numbers of children in South Africa already live in poverty, in situations that violate many of their basic rights. HIV will serve only to worsen their plight. The following section examines the impacts of the epidemic, focusing on poverty and the impact on children who have been orphaned or who are living with HIV-infected adults.

**Poverty:** Of the 17.3 million children in South Africa, about 12 million are classified as living in poverty, according to household income indicators. Estimates of the child poverty rate in South Africa vary between 60 per cent (May et al. 1998) and 72 per cent (Haarmann 1999). These estimates are based on income poverty lines and only the Haarmann study looks at household spending per child as opposed to household income. Such figures provide a baseline for looking at broad trends but not for assessing children’s quality of life. There is a critical lack of data on child poverty trends and causal factors in South Africa.

Poverty, unemployment and inequality are increasing in South Africa. Income distribution is among the most unequal in the world. In 1996, almost 57 per cent of the population were living in poverty, and of these, two thirds were black Africans. Racial inequalities persist; white South Africans’ per capita income is almost nine times higher than that of black South Africans.

Food insecurity regularly affects 30 per cent of households where children live. The majority of South African children live in overcrowded homes with pit latrines. Water supply in rural areas remains variable.

**Children orphaned by AIDS:** There have been many international and national studies looking at the ‘orphan problem’. Most concentrate on the issue of scale, the crisis of unmanageability, the imperative of community-based care. Few look at the impact of being orphaned on individual children, or on children and adults in the households into which they are ‘absorbed’. Studies have examined the wide range of socioeconomic impacts experienced by children and families in poor, HIV-affected families (Whiteside 1998). These point to the all-encompassing breakdown that can begin with the diagnosis or the suspicion of HIV infection in a family.

**Child-headed households:** There is very limited information on child-headed households in South Africa. Households may be headed by employed adult siblings of
orphans, by school-going older siblings, by children looking after each other with adult support from another household, or by children caring for a dying parent with no adult support. As the adult mortality rate peaks, there are likely to be many more households of this nature. The Durban-based Children’s Rights Centre stresses the need for more reliable information on the whereabouts and situation of orphaned children, in order to assess vulnerability and need for support. When a child becomes a caregiver for an adult infected with HIV, his or her childhood is effectively sacrificed. Already some NGOs and CBOs find themselves offering training and support to children who are fulfilling adult roles at the expense of their own security and development.

**Violence, child abuse and neglect:** Violence, abuse and neglect of children are on the increase in South Africa. Domestic violence is common among HIV-infected families and has become one of the major stumbling blocks to disclosure among married women in South Africa. The fear of disclosure makes it difficult for women to make informed decisions. They are therefore forced into continued childbearing and breastfeeding that may significantly compromise the health of their children.

Sexual and physical abuse of children increased by 117 per cent between 1993 and 1996. In 1998 there were approximately 34,000 reports of crimes against children, including rape, incest, kidnapping, etc (ACESS 2001). The reported cases of children being victims of abuse, neglect and other forms of violence have increased dramatically since the late 1990s, when data were last made available. There are no official national data on the number of children who are victims of commercial sexual exploitation.

According to the South African Police Services, 15,650 child rape cases were reported between January and September 2002. Of these, 5,859 concerned children between 0–11 years and 9,791 children between 11–17 years. The South African National Council for Child and Family Welfare (1999) has found that children most affected by abuse are between the ages of 10 and 14 years old. There is increasing concern that the age of children committing sexual offences is also decreasing.

**Abandonment/children on the streets:** Abandonment happens at two levels. The first is the abandonment of the family by a caregiver/breadwinner. It is commonplace to hear of women whose partners or husbands abandoned them when they disclosed their HIV status. The second is the abandonment of the child. The South African National Council for Child and Family Welfare (1999) has found that children most affected by abuse are between the ages of 10 and 14 years old. There is increasing concern that the age of children committing sexual offences is also decreasing.

There is a general lack of data on the number of street children in South Africa. Experts believe that the number of children living on streets is increasing gradually due to poverty and HIV.
 Household impacts

The HIV epidemic results in many impacts, the majority of which affect children directly or indirectly. Few, however, are as serious and affect children more than the impact felt at the household level. Data from a household survey conducted in Free State province from 2001 to 2003 is presented and discussed below (Booysen et al. 2003). The study involved a detailed household questionnaire that was administered in two areas, one rural and one urban. In each area, households containing an HIV-positive adult were sampled and balanced by households not directly affected. The sample of affected households was selected based on referrals from home-based care organizations in the area. The non-affected households were randomly selected from each area and screened for negative signs of HIV infection with the use of a questionnaire. However, the sampling of non-affected households only attempted to select those not affected by HIV-related illness at the time of the interview and did not attempt to screen them in terms of the other ways in which they were indirectly affected by the epidemic (e.g. having to give shelter to orphaned children or having to care for friends and family members in neighbouring households).

**Household size and structure:** Although affected households appear to be larger, suggesting a greater supply of labour, dependency ratios are also greater, implying that households affected by HIV in fact have a smaller supply of labour than non-affected households, with a larger proportion of the household consisting of children and elderly persons.

<table>
<thead>
<tr>
<th></th>
<th>Urban Affected</th>
<th>Urban Non-affected</th>
<th>Rural Affected</th>
<th>Rural Non-affected</th>
<th>Total Affected</th>
<th>Total Non-affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average household size</td>
<td>5.6</td>
<td>4.6</td>
<td>4.5</td>
<td>4.1</td>
<td>4.7</td>
<td>5.1</td>
</tr>
<tr>
<td>Dependency ratio</td>
<td>36.5</td>
<td>32.0</td>
<td>34.3</td>
<td>34.0</td>
<td>34.2</td>
<td>35.4</td>
</tr>
<tr>
<td>Sample size (n)</td>
<td>101</td>
<td>100</td>
<td>101</td>
<td>104</td>
<td>406</td>
<td>202</td>
</tr>
</tbody>
</table>

**Household composition (%):**

- Nuclear family: 73.8 83.2 72.2 80.9 77.5 73.0 82.0
- Extended family: 24.4 15.9 27.3 18.6 21.5 25.9 17.2
- Non-related persons: 2.2 1.0 0.0 0.3 0.8 1.1 0.6

**Total:** 100.0 100.0 100.0 100.0 100.0 100.0 100.0

**Average unemployment rate (%):**

- Narrow: 55.2 48.8 70.1 61.0 57.8 61.6 54.3
- Broad: 57.9 50.0 72.5 62.8 59.9 64.2 55.8

In addition, morbidity and mortality occur more often in affected households than in non-affected households; in 73 per cent of affected households one or more members
had experienced chronic illness in the past month, while 20 per cent had lost one household member in the six months before the interview. In non-affected households, only 20 per cent of households were affected by morbidity and 1 per cent by mortality.

Table 3. Income and composition of income

<table>
<thead>
<tr>
<th></th>
<th>Urban Affected</th>
<th>Urban Non-affected</th>
<th>Rural Affected</th>
<th>Rural Non-affected</th>
<th>Total Affected</th>
<th>Total Non-affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average monthly</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>household income (Rands)</td>
<td>1630</td>
<td>2692</td>
<td>948</td>
<td>1596</td>
<td>1727</td>
<td>1296</td>
</tr>
<tr>
<td>Average monthly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>per capita income (Rands)</td>
<td>335</td>
<td>741</td>
<td>232</td>
<td>417</td>
<td>434</td>
<td>285</td>
</tr>
<tr>
<td>Average monthly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>adult equivalent income (Rands)</td>
<td>614</td>
<td>1211</td>
<td>397</td>
<td>694</td>
<td>734</td>
<td>508</td>
</tr>
<tr>
<td>Sample size (n)</td>
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<td>100</td>
<td>95</td>
<td>99</td>
<td>393</td>
<td>194</td>
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<tr>
<td>Composition of income (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment income</td>
<td>58.4</td>
<td>67.4</td>
<td>31.1</td>
<td>41.4</td>
<td>49.8</td>
<td>45.0</td>
</tr>
<tr>
<td>Non-employment income</td>
<td>33.9</td>
<td>24.7</td>
<td>40.9</td>
<td>30.8</td>
<td>32.4</td>
<td>37.3</td>
</tr>
<tr>
<td>Remittance income</td>
<td>7.6</td>
<td>7.8</td>
<td>21.7</td>
<td>25.4</td>
<td>15.5</td>
<td>14.5</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Note: the sample sizes differ from the interviewed samples in table 2 because data were not available for all households.

Income and expenditure: HIV infections are concentrated among members of the economically productive age group (15 to 49 years). Infection often leads to the loss of earners within the household. As expected, affected households were found to have lower incomes than non-affected households, measured at the household or individual level or in adult equivalent terms. The fact that affected households were generally larger than non-affected households means that fewer resources were being shared among a larger number of persons. Per capita and adult equivalent income in affected households represented between 50 per cent and 60 per cent of the levels of income in non-affected households.

There were also significant differences in the income composition of affected and non-affected households. Affected households were more dependent on non-employment sources of income (consisting primarily of government grants) and a lower proportion of their income was derived from employment. This is understandable, given that affected households face higher dependency ratios, are more subject to morbidity and mortality and face higher unemployment levels.

Average monthly household expenditure, per capita monthly expenditure and adult equivalent monthly expenditure were lower in the affected group of households than
in the non-affected group. Although differences are not particularly pronounced in terms of total household expenditure, the fact that affected households have more members means that per capita and adult equivalent expenditure is 30–40 per cent less than the levels of expenditure in non-affected households.

The survey also found differences in patterns of expenditure. In the case of illness, a larger proportion of household resources are allocated to spending on food, health care and household maintenance, while a smaller share goes to education, clothing, personal items and durables. Transport and rent differences are very small. Households affected by death in turn spend relatively more of their available resources on food, health care, clothing and rent and a smaller share on education, household maintenance, transport and personal items, compared to households where no death has occurred. The differences in the share of durables in total regular household expenditure are fairly small.

Table 4. Expenditure patterns in households affected by morbidity and mortality

<table>
<thead>
<tr>
<th></th>
<th>Morbidity</th>
<th>Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Illness</td>
<td>No illness</td>
</tr>
<tr>
<td>Composition of regular expenditure (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food</td>
<td>51.8</td>
<td>48.0</td>
</tr>
<tr>
<td>Education</td>
<td>1.8</td>
<td>4.6</td>
</tr>
<tr>
<td>Health care</td>
<td>4.7</td>
<td>3.0</td>
</tr>
<tr>
<td>Household maintenance</td>
<td>21.0</td>
<td>19.5</td>
</tr>
<tr>
<td>Transport</td>
<td>7.2</td>
<td>7.1</td>
</tr>
<tr>
<td>Clothing</td>
<td>1.9</td>
<td>2.9</td>
</tr>
<tr>
<td>Rent</td>
<td>1.6</td>
<td>1.4</td>
</tr>
<tr>
<td>Personal items</td>
<td>2.9</td>
<td>3.7</td>
</tr>
<tr>
<td>Durables</td>
<td>7.1</td>
<td>9.8</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Coping financially: Households generally have three alternatives in terms of coping with changes in income and expenditure, i.e. to borrow money, to utilize savings, or to sell assets. The most frequent responses seem to be borrowing, followed by the utilization of savings and the sale of assets.

The purpose for which the households borrow money also suggests that the HIV epidemic plays a role in causing households to take on increasing levels of debt. The majority of responses by affected households indicate that the money is used to pay for funerals and medical expenses, whereas most non-affected households indicate that the money is spent on education, durables and clothing.
Impacts on children: The impacts outlined above have numerous implications for the children living within the two types of households. Two specific issues related to the impact of HIV on children were briefly explored in more detail. Firstly, the extent to which the school enrolment of children in affected and non-affected households may differ. A distinction was made between children aged 7–13 (primary school), aged 14–18 (secondary school) and aged 7–18 years (all children of school age). The second issue explored is of orphaned children, which should give an indication of the extent of the problem, not only in affected households but also in non-affected households, which may also provide shelter to orphaned children. In addition, school enrolment of orphans was compared across affected and non-affected households, while the characteristics of those households sheltering orphans were also explored.

Children orphaned by AIDS: On average, 8 per cent of children aged 15 years and under lost their mother, 28 per cent their mother or father and 3 per cent both mother and father. This suggests a relatively high incidence of paternal orphanhood. An almost equal number of orphans are male and female.

Table 5. Number of orphaned children

<table>
<thead>
<tr>
<th></th>
<th>Urban Affected</th>
<th>Urban Non-affected</th>
<th>Rural Affected</th>
<th>Rural Non-affected</th>
<th>Total Affected</th>
<th>Total Non-affected</th>
<th>Total P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No %</td>
<td>No %</td>
<td>No %</td>
<td>No %</td>
<td>No %</td>
<td>No %</td>
<td></td>
</tr>
<tr>
<td>Total children aged</td>
<td>214 100</td>
<td>149 100</td>
<td>165 100</td>
<td>153 100</td>
<td>681 100</td>
<td>379 100</td>
<td>302 100</td>
</tr>
<tr>
<td>fifteen or under</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children who lost</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>their mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Male</td>
<td>11 38 5 71 7 64 4 57 27 50 18 45 9 64</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Female</td>
<td>18 62 2 27 4 36 3 43 27 50 22 55 5 36</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children who lost</td>
<td>56 26 24 16 51 31 57 37 188 28 107 28 81 27</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>one parent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Male</td>
<td>22 39 10 42 24 47 29 51 85 45 46 43 39 48</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Female</td>
<td>34 61 14 58 27 53 28 49 103 55 61 57 42 52</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children who lost</td>
<td>12 6 3 2 4 2 4 2.6 23 3 16 4 7 2</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>both parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Male</td>
<td>4 33 3 100 3 75 2 50 12 52 7 44 5 71 0.007</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Female</td>
<td>8 67 0 0 1 25 2 50 11 48 9 56 2 29 0.004</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

A significantly larger percentage of children in affected households lost their mother or both parents when compared to non-affected households. The percentage of children in affected households who lost either parent is only slightly higher.
than that in non-affected households. Hence, the results indicate that, although a larger number of orphans are to be found in affected households, non-affected households also shelter a number of orphans. This is understandable, insofar as the extended family often absorbs orphaned children.

Orphaned children are sheltered primarily by households that are headed by females, with 76 per cent of orphans living in female-headed affected households and 89 per cent being cared for in non-affected households led by women. A large proportion of those caring for orphans were running households on their own: of the non-affected households, 68 per cent were headed by widows or widowers, and 18 per cent by those who were divorced or separated. There was a similar case for affected households that shelter orphans: 65 per cent were headed by widows or widowers, and 21 per cent by married persons. The fact that some affected households already sheltered orphans means that, apart from having to care for older affected members, they also had to take responsibility for the children of deceased members of their extended family.

Table 6. Demographic characteristics of households sheltering children who have lost at least one parent

<table>
<thead>
<tr>
<th></th>
<th>Urban Affected</th>
<th>Urban Non-affected</th>
<th>Rural Affected</th>
<th>Rural Non-affected</th>
<th>Total Affected</th>
<th>Total Non-Affected</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of children who lost at least one parent</td>
<td>56 100</td>
<td>24 100</td>
<td>52 100</td>
<td>57 100</td>
<td>189 100</td>
<td>108 100</td>
<td>81 100</td>
</tr>
<tr>
<td>Gender of household head:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16 29</td>
<td>2 8</td>
<td>10 19</td>
<td>7 12</td>
<td>35 19</td>
<td>26 24</td>
<td>9 11</td>
</tr>
<tr>
<td>Female</td>
<td>40 71</td>
<td>22 92</td>
<td>42 81</td>
<td>50 88</td>
<td>154 82</td>
<td>82 76</td>
<td>72 89</td>
</tr>
<tr>
<td>Marital status of household head:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married (civil)</td>
<td>19 34</td>
<td>1 4</td>
<td>4 8</td>
<td>1 2</td>
<td>25 13</td>
<td>23 21</td>
<td>2 3</td>
</tr>
<tr>
<td>Married (traditional)</td>
<td>0 0</td>
<td>0 0</td>
<td>3 6</td>
<td>4 7</td>
<td>7 4</td>
<td>3 3</td>
<td>4 5</td>
</tr>
<tr>
<td>Widow/widower</td>
<td>29 52</td>
<td>18 75</td>
<td>41 79</td>
<td>37 65</td>
<td>125 66</td>
<td>70 65</td>
<td>55 68</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>4 7</td>
<td>3 13</td>
<td>0 0</td>
<td>12 21</td>
<td>19 10</td>
<td>4 4</td>
<td>15 19</td>
</tr>
<tr>
<td>Never married</td>
<td>4 7</td>
<td>2 8</td>
<td>4 8</td>
<td>3 5</td>
<td>13 7</td>
<td>8 7</td>
<td>5 6</td>
</tr>
<tr>
<td>Average household size</td>
<td>7.8</td>
<td>7.0</td>
<td>5.6</td>
<td>5.6</td>
<td>6.1</td>
<td>6.2</td>
<td>6.0</td>
</tr>
<tr>
<td>Average age of household head</td>
<td>55.1</td>
<td>45.8</td>
<td>56.5</td>
<td>55.2</td>
<td>54.3</td>
<td>55.8</td>
<td>52.4</td>
</tr>
</tbody>
</table>
**Conclusions:** The devastating impact that HIV infection and the ensuing illness and death have on members of affected households is starkly illustrated. These households face a shrinking supply of labour and income at the same time as the need for both increases. Children in these households face many risks. Expenditure on food, clothing and education falls, placing the health and rights of children at risk. After the death of a parent, children are faced with great uncertainty. It is at the household level where many of the impacts discussed in this chapter begin and it is at this level where many of the responses should focus.

**Responses**

The impacts outlined in the proceeding sections have not occurred without re-sponse. Individuals, communities, FBOs, NGOs, businesses and government have responded in various ways. To review all of these would be a major paper in itself. This study focuses on government response.

Prior to 2002, the response of the national and provincial governments in terms of policies, resources committed and services delivered to respond to HIV were very limited. However, due to a concerted public campaign by civil society, primarily around the issue of treatment of people living with HIV (PLHIV), many more resources have been committed to ameliorating the impacts of the epidemic. These resources have primarily been allocated towards health, but significant funding increases to education and welfare programmes have also occurred, as table 7 indicates.

**Table 7. National budget allocations to HIV and AIDS, 2001/02–2006/07, Rand millions**

<table>
<thead>
<tr>
<th>Department</th>
<th>2001/02 (R)</th>
<th>2002/03 (R)</th>
<th>2003/04 (R)</th>
<th>2004/05 (R)</th>
<th>2005/06 (R)</th>
<th>2006/07 (R)</th>
<th>Total (6 Years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
<td>265</td>
<td>459</td>
<td>766</td>
<td>1,212</td>
<td>1,545</td>
<td>2,008</td>
<td>4,765</td>
</tr>
<tr>
<td>Social welfare</td>
<td>14</td>
<td>51</td>
<td>70</td>
<td>78</td>
<td>85</td>
<td>89</td>
<td>252</td>
</tr>
<tr>
<td>Education</td>
<td>62</td>
<td>133</td>
<td>131</td>
<td>128</td>
<td>136</td>
<td>144</td>
<td>409</td>
</tr>
<tr>
<td>Science</td>
<td>0</td>
<td>2</td>
<td>5</td>
<td>19</td>
<td>30</td>
<td>26</td>
<td>76</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>343</strong></td>
<td><strong>646</strong></td>
<td><strong>973</strong></td>
<td><strong>1,439</strong></td>
<td><strong>1,797</strong></td>
<td><strong>2,268</strong></td>
<td><strong>5,504</strong></td>
</tr>
<tr>
<td><strong>Real terms</strong></td>
<td><strong>395</strong></td>
<td><strong>677</strong></td>
<td><strong>973</strong></td>
<td><strong>1,365</strong></td>
<td><strong>1,616</strong></td>
<td><strong>1,939</strong></td>
<td><strong>4,920</strong></td>
</tr>
<tr>
<td><strong>Real growth rate</strong></td>
<td>49%</td>
<td>71%</td>
<td>44%</td>
<td>40%</td>
<td>18%</td>
<td>20%</td>
<td>26%</td>
</tr>
</tbody>
</table>


With slowly increasing resources early in this decade, service delivery difficulties were experienced and take-up rates of national government money by the provinces was problematic. This resulted, for example, in the Eastern Cape in 2000/01 only spending 26 per cent of their allocated HIV funds. These vastly increased amounts of resources indicated in table 7 will cause a major logistical problem in delivering services to those infected and affected by HIV.
The National HIV/AIDS and STD Programme was operationalized in 1995 by the National AIDS Directorate in the Department of Health (mainly concerned with policy) and nine Provincial HIV/AIDS Programmes (mainly concerned with programme delivery). In addition, a number of NGOs were either funded or subcontracted to run projects or to provide services.

**HIV/AIDS and STD Strategic Plan for South Africa 2000–2005**

Early in 2000, an HIV/AIDS and STD Strategic Plan (2000–2005) was developed. It stated that all stakeholders would use this document for planning. In 2000, a target of R10 per person per year was set as the resource standard, making a total of R400 million per year for the whole country. Political pressure resulted in this very modest target being surpassed.

The strategic plan is designed not only for the health sector, but rather to guide the country’s response as a whole. It is meant as a framework, and it was envisaged that it would be used as a basis for the development of strategic and operational plans for government departments and other organizations.

The primary goals of the plan are to:

- Reduce the number of new HIV infections (especially among young people).
- Reduce the impact of HIV on individuals, families and communities.

Its objectives are described as follows:

- Establish and implement integrated community-based care and support programmes for children infected and affected by HIV.
- Improve access to VCT services for 12.5 per cent of the population aged 15–49, over three years, focusing on young people and rural communities.
- Implement the life skills and HIV education programme in 20 per cent of primary and secondary schools in the first year, a further 40 per cent the next year, and 40 per cent in year three, ensuring 100 per cent coverage by 2002/03.
- Mobilize communities through community-based HIV awareness programmes.


The Government’s mitigation attempts for children are being led by NIP and this in turn is guided by the broader HIV/AIDS and STD Strategic Plan for South Africa 2000–2005.
The aim of NIP is: ‘To ensure access to an appropriate and effective integrated system of prevention, care, and support services for children infected and affected by HIV/AIDS’. NIP combines the efforts of three key government departments, Education, Health and Social Development, and focuses their efforts on expanding access to the following key programmes areas:

- Life skills education
- Home/community-based care and support
- Voluntary counselling and testing (VCT)
- Poverty relief.

Health responses

The health sector response is primarily around a variety of health interventions including:

- VCT
- Prevention of mother-to-child transmission (PMTCT) of HIV
- Provision of antiretroviral drugs (ARV).

Education response

In South Africa, education consumes almost a quarter of the national budget and employs or enrols almost a third of the country’s population. Moreover, educator salaries account for well over 90 per cent of the education budget, confirming that the HIV impact in this sector is of strategic and budgetary significance.

The main HIV activities are life skills and HIV education in primary and secondary schools.

**Life skills programme:** In 1999 the National Cabinet approved funds amounting to R450 million for an integrated response to the epidemic, focusing on children and young people. In 2000/1, R75 million was allocated to the strategy – 57 per cent of which was for life skills education.

In 1997, 840 master trainers and 9,034 secondary school teachers were trained in life skills and HIV, and quantities of materials were purchased to resource the schools. This programme was managed by the Department of Health – only recently has the Department of Education taken over as the lead department. The roll-out of this programme is planned to potentially reach 21,304 primary schools and 8,497,388 primary school learners. The effectiveness of these interventions has not yet been fully evaluated. Such an evaluation would allow the refinement and appropriate supplementation of the intervention to increase effectiveness.
In support of the life skills programme, a youth programme (the South African AIDS Youth Programme or SAYP) has been established, which targets young people through social mechanisms and youth organizations. In the area of life skills programmes for young people, the challenge remains to utilize peer education on a large scale as an effective way to influence adolescent sexual behaviour. Discrete projects, for both in- and out-of-school young people, offer hope of success, but these have not been rolled out on any large scale.

Welfare response

Family/community response: The main measures to reduce the impact of HIV on children have clearly been taken by individuals and households, who have absorbed nearly all of the country’s orphans into their extended families and cared at home for those dying of HIV-related illnesses. While community workers in different parts of the country see some remaining capacity for absorbing orphans, the support structures on which extended family or community fostering depends are already under severe strain.

Civil society response: The various elements of civil society are attempting to respond to the problems faced by HIV-affected and infected children by:

- Mobilizing caregivers in the community to support affected children.
- Providing training and support to caregivers.
- Assisting caregivers and children to access services and social grants to which they are entitled.
- Lobbying and fundraising around the additional needs of children affected by HIV and poverty.

The first task is central to the survival and well-being of the child, but its achievement is increasingly dependent on organizations delivering in all the other areas. Many community-based projects have started out with a specific HIV focus but have developed a holistic approach, given the spectrum of crises facing HIV-affected children. Confronted by huge gaps in service delivery, they are often over-stretched in terms of the range of HIV-affected children’s needs – from food security to medication, education to foster care.

Government welfare policies for children: Most of the welfare burden of HIV has been shouldered by individuals, families and communities. At present, there are three welfare grants available to children. These are the child support grant, the care dependency grant and the foster grant that are paid by provincial social development departments through their social security budgets.

The Child Support Grant in 2004 was R170 per child per month. The maximum yearly household income for assistance was R13,200. Children under the age of 11
years are eligible, although this is being extended to 14 years. Because HIV is throwing increasing numbers of children below the income poverty line, the epidemic is making growing numbers of children eligible for the grant.

The Foster Grant was R530 per child per month in 2004. There is also a means test for eligibility. The annual income of the foster parent must not exceed twice the annual foster child grant. Only children who have been placed in the care of foster parents by a court of law are eligible for the grant. Each foster parent or parents can access grants for a maximum of six children. Increasing numbers of children will become eligible for this grant as courts place the rising numbers of children affected by HIV in foster care.

The Child Dependency Grant was R740 per child per month in 2004. The means test for this grant is that the combined annual income of the family, after deductions, must not exceed R48,000 per annum. This grant is for children with severe mental or physical disabilities who require permanent home care. But there is no specific provision for children with chronic illnesses, including AIDS.

Table 8 shows that considerable efforts have been made to increase the number of beneficiaries, although for those living in rural areas without transport or the requisite identification documents, access is still problematic.

<table>
<thead>
<tr>
<th>Number of beneficiaries of child-specific grants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of beneficiaries</td>
</tr>
<tr>
<td>--------------------------</td>
</tr>
<tr>
<td>Foster Grant</td>
</tr>
<tr>
<td>Care Dependency Grant</td>
</tr>
<tr>
<td>Child Support Grant</td>
</tr>
</tbody>
</table>

Source: Department of Social Development database.

**Recommendations for action**

Efforts to mitigate the impact of HIV on children require the involvement of many sectors of government, civil society and communities. To draw together and coordinate such a response, strong and committed leadership is essential.

**Health**

In general, in South Africa, levels of awareness of HIV and AIDS are high (though some myths and misconceptions persist). There is, however, little evidence of behaviour change. This is indicative of the complex nature of perceived vulnerability and the lack, particularly for young people and other vulnerable groups, of any real self-sufficiency in sexual decision-making.
That stated, how has South Africa responded to the prevention challenges? Among the significant prevention achievements in the period from 1997 to 2004 are: the life skills programme, mass media campaigns, the STI programme and the condom programme.

**Life skills programmes for youth:** One life skills product that has been successfully and extensively used is Stepping Stones, a workshop series designed to promote sexual and reproductive health. It addresses questions of gender, sexual health, HIV and AIDS, gender violence, communication and relationship skills. In doing so, it recognizes that sexual relationships are always situated within a broader context of relationships with sexual partners, families and the community or society in which people live. These influences substantially determine how people behave.

**Mass media campaigns:** The Beyond Awareness communication campaign, recognizing that the levels of awareness around HIV and AIDS were in fact high, took the debate to a more personal level, encouraging people to confront their vulnerability, and linking them to resources such as the AIDS Helpline, operated by Life Line.

Beyond Awareness II was a multimedia communication campaign that was conducted in two phases over a three-year period (1998–2000). The objectives of the campaign were to:

- Intensify communication of key messages around the HIV epidemic directed primarily at young people.
- Develop and distribute communications resources to support action around HIV and AIDS.
- Promote social action through targeted projects. Specifically these included the AIDS Memorial Quilt Project, a Tertiary Institutions Project and a Media Workers Project.
- Build capacity among HIV communicators and strategists through conducting key research.
- Conduct appropriate behavioural research in support of HIV communication and evaluate various aspects of the campaign.

**STI management:** As discussed earlier, the presence of an STI dramatically increases the likelihood of HIV infection. The STI programme remains one of the pillars of the National AIDS Programme by ensuring consistent supplies of drugs, promoting awareness and health-seeking activities, and training health care providers in both the public and private sectors. Support materials have been produced on STIs and their links with HIV.

**Condom programme:** The Department of Health has prioritized condom distribution through a systematic annual procurement programme, supported by
distribution through clinics and other sites (71 per cent of condom users report that they obtain supplies from clinics or community health centres). Access to barrier methods, primarily male condoms, has been greatly improved despite some problems with quality control. Some 250 million condoms were distributed free in 2002.

Despite improved access, there are still significant barriers to condom use in certain areas, particularly for young people. A survey conducted by Condom Concepts and Latex Surgical Products highlighted that young adults do not trust free condoms and think they are of inferior quality.

**Prevention of mother-to-child transmission (PMTCT) of HIV:** The need to introduce a PMTCT programme in South Africa was first recognized in 1988, when a proposed programme was costed on behalf of the Department of Health. The total cost for introducing this programme – including supplementary staff, staff training, test kits, drugs at a discounted price and milk formula – in all antenatal clinics in the public sector throughout the country was R80 million. The Department considered this figure excessive and the proposal was not pursued.

Planning for the implementation of a national PMTCT programme was at an advanced stage in 2002. The programme was to have been introduced in at least two sites in all nine provinces as a two-year pilot project to resolve funding and logistical problems before the widespread introduction of the programme throughout the country. The programme incorporated VCT to identify HIV-positive women, antenatal interventions, modified midwifery practices and treatment with nevirapine, followed after the birth by medical support for mother and child, free milk substitutes for six months, vitamin supplements and prophylaxis for opportunistic infections. However, as of end-2004, this programme was still awaiting Government support and funding for full implementation.

**Treatment and care of HIV-infected children:** No objectives exist in the national strategic plan specifically related to the treatment of HIV-positive children. However, children are included as recipients of care and treatment strategies. Provincial and national guidelines have been developed on the management of HIV-infected children as well as on the use of ARV drugs, but further training and improved support services and infrastructure are needed if they are to be followed at all levels.

Such training and health system upgrading would also be beneficial for supporting home-based models of care. Home-based care has been found to be very effective in reducing the rate of hospitalization and length of stay in hospital, decreasing the impact of HIV on primary health care services, lowering costs, supporting the family and increasing compliance with treatment regimes (Johnson et al. 2001).
Education

According to the South African Population Census, in 1996 there were an estimated 1.3 million children between the ages of 7 and 18 out of school, with the provinces of the Eastern Cape and KwaZulu-Natal the worst affected. There is, however, no information on the reasons for this figure, which equates to more than 10 per cent of the enrolled school population. Thus, the advent of AIDS-related morbidity and mortality will build on already high levels of voluntary or enforced exclusion, aggravating the impact on education, and contributing to the decline in enrolments, transition rates and output from the system.

**Overall Government education response:** For the public education system to survive as an effective delivery mechanism for teaching and learning, it is vital that its administrators take a long-term view of the impact of HIV, which will inevitably exacerbate the existing high attrition rates for educators and managers. Consequent conditions and service ratios may therefore condemn declining cohorts of learners to deteriorating quality and standards of achievement for the foreseeable future.

Clearly, an adequate response to the challenge of AIDS requires both a systemic and sustainable management effort, together with development of appropriate curricula, and relevant sexual and reproductive health education materials, in order to effect behaviour change.

Welfare

**Government responses:** The South African Government has committed line ministries to providing a continuum of care for vulnerable children and expresses commitment to integrating HIV care and support across sectors. Further coordination is now needed at national, provincial and grassroots level. Government policy with regard to the care of children orphaned by AIDS, according to former Deputy Director of HIV/AIDS in the Department of Social Services and Population, Sakina Mohammed, is to concentrate on “empowering the community to take care of orphans”. It is felt that institutions are a short-term solution with long-term negative implications for child welfare. The state has placed a moratorium on setting up new homes and is concentrating instead on foster care. Ninety four per cent of institutional places for children have been closed, and it is hoped that the funds saved will soon be allocated to support foster care. Nevertheless, despite the Government’s moratorium, new institutions are appearing with the support of FBOs, NGOs and the private sector. Effort needs to be made to redirect funds and energy to the support and development of community-based models of care, so that children are not left on their own to care for their sick parents.
References and Bibliography


Chapter 5

Children Affected by HIV and AIDS in the Aftermath of the Successful Control of an HIV Epidemic: The Case of Thailand

Wattana S. Janjaroen and Suwanee Khamman

Introduction

The first AIDS case was detected in Thailand in 1984. A decade later, HIV had spread to the general population; a June 2000 HIV serosurveillance survey showed that the low rate of reduction of transmission via commercial sex had led to the spread of HIV to low-risk partners and children. Indeed, the prevalence of HIV in pregnant women was 1.74 per cent in 1997 and increased to 2.02 per cent in 1999. This has inevitably given rise to HIV infection among children. The Thai Working Group on HIV/AIDS Projection (March 2001) indicated that approximately 4,000 Thai children are being infected with HIV each year. The National Economic and Social Development Board (NESDB) estimated that 63,000 children would be directly infected with HIV and 47,000 would die of AIDS by the year 2000. It was also estimated that by the year 2001, over 289,000 children under the age of 15 would have lost their mothers and by 2005, this figure would have risen to 380,000 (UNAIDS, UNICEF and USAID 2002).

Thus, a growing number of children will be affected by HIV. Fewer children and their families will be able to afford education because of loss of family income due to illness or death from AIDS. Many will be unable to complete their education because of the need to work or care for their ill family members. The illness and death of family members causes trauma and often leads to social discrimination and stigmatization at school.

Faced with the growing crisis, the Thai Government, NGOs and civil society have worked together to combat the epidemic and the results have been dramatic. An epidemiological model by the Thai Working Group on HIV/AIDS Projections (March 2001) shows that the annual number of new infections peaked in the early 1990s and then declined by more than 80 per cent in 1993. It estimated that 200,000 fewer people had been infected with HIV than would have been the case...
if the upward trend had continued. The Thai experience demonstrates that effective national responses are those that draw on commitment at the highest levels of political leadership, effectively employ social capital and involve civil society, use focused programmes to guide and test policy, and draw upon institutional and traditional approaches in an overall holistic, people-centred approach – empowering individuals, families and communities to protect and care for themselves.

With no cure for AIDS currently available, planning for mitigation of the epidemic must involve long-term and broad-scale commitment to prevention programmes, especially for those in high-risk groups, such as children born to infected mothers, teenagers, injecting drug users (IDU), ethnic minorities and migrants.

Thai society also needs to be ready to cope with the increasing problems of children orphaned by AIDS, by building and strengthening government, family and community capacity to provide a supportive environment for them. This will entail the provision of appropriate counselling and psychosocial support, efforts to ensure non-discrimination and full and equal enjoyment of child rights, increasing linkages between HIV interventions and development programmes, as well as more effective and expanded coordination for HIV planning at the national and provincial levels. It is important to enhance the role of local authorities and communities, and to mobilize groups of people affected by HIV, community-based organizations (CBOs) and NGOs, in order to provide better care for people living with HIV and their families.

This chapter reviews and analyses the past and expected evolution of HIV incidence and AIDS mortality in Thailand. Intervention programmes designed for the prevention, treatment and mitigation of HIV and related illnesses will be studied and analysed to reflect on whether or not they are effective responses to the impacts of the epidemic.

The chapter looks at both the demand and supply sides of the problem. In-depth interviews and focus group discussions were conducted to: (i) explore demand for, and satisfaction with, HIV prevention and control programmes; and (ii) look into the responses and needs of service providers and receivers as evidence for developing effective policy and implementation plans.

The evolution of Thailand’s HIV epidemic

The HIV situation in Thailand has gone through three major phases, as outlined in table 4.

Phase I: Health focus 1984–1990

The first wave of HIV infection was considered a medical health problem since it had an impact on individual health similar to a chronic disease and was concentrated in specific demographic groups: homosexuals and those who had sexual relations with
foreigners. The epidemic then spread to IDUs, whose infection rate rapidly increased from below 1 per cent in late 1987 to over 40 per cent in late 1998. The epidemic later spread to heterosexuals, particularly men who visited sex workers (SWs).

From 1984 to 1990, as HIV was treated solely as a disease, it was the responsibility of the Ministry of Public Health’s (MoPH) Department of Communicable Disease Control. The Government focused on the medical and health aspects of prevention and surveillance among male homosexuals and IDUs. It was believed that AIDS was an epidemic only among the identified risk groups, so the general population did not need to be given much information about it. Moreover, the Government and business were concerned about the likely impact of publicity about HIV and AIDS on the tourist industry.

**Organization structure:** The Department of Communicable Disease Control provided care and treatment under the general umbrella of the MoPH. In 1987, the AIDS Coordination Committee was appointed to coordinate an HIV control programme between public and private hospitals. As HIV infection continued to expand, in 1990 the Government established the National AIDS Prevention and Control Organization, to serve as the national body for AIDS policy with the Minister of Public Health as chairman. The Organization’s major task was policymaking and setting strategies for HIV prevention and control. It was complemented by the multisectoral National AIDS Prevention and Control Committee (NAC), chaired by the Prime Minister, with the Permanent Secretary of MoPH as the Secretary. The Committee later appointed seven subcommittees to coordinate HIV activities among public and private agencies and NGOs.

**Programmes and projects:** In 1988, a budget of 4.6 million Baht was allocated directly to HIV prevention and control programmes. The AIDS budget was then increased from 11.1 million Baht in 1989 to 66.6 million Baht in 1990. Most of the projects were short and medium term, based on WHO guidelines. Activities focused on prevention and control of HIV infection among IDUs; prevention of sexual transmission by promoting safe sex, condom use and condom distribution; prevention of transmission through blood transfusion by blood screening tests; and provision of social welfare, research, and monitoring and evaluation.

**Phase II: Social focus 1991–1996**

**Situation:** By the early 1990s, HIV had spread to the general population. In 1994, HIV prevalence reached 31 per cent among brothel-based SWs (increasing from only 3.12 per cent in 1989). Infection in this group was high because it was the virus subtype E, which transmits more readily than virus subtype B, found among IDUs and the male homosexual group. For SWs not based in brothels, HIV prevalence increased slowly from 0 per cent in 1989 to 8 per cent in 1994. In 1995, HIV prevalence among SWs of both types was 17.8 per cent (figure 1). From 1996 to
1999, HIV prevalence then decreased, due to active HIV prevention and control activities implemented by both public and private agencies.

Figure 1. HIV prevalence among sex workers in Thailand, 1989–1999

HIV prevalence in males at STI clinics increased from 2.5 per cent in 1990 to 8.5 per cent in 1994 and dropped to 6.8 per cent in 1997, but increased again to 9 per cent in 1999 (figure 2).

Figure 2. HIV prevalence among male STI clients in Thailand, 1989–1999

Source: Division of Epidemiology, Ministry of Public Health.
HIV prevalence in successive cohorts of 21-year-old conscripts in the Royal Thai Army (a nationally representative sample of young men and the group that comprises the prime clients of SWs) rose from 0.5 per cent in 1989 to a peak of about 4 per cent in 1993, and then decreased to 0.8 per cent in 2000 (figure 3). Since army conscripts were young, their infections could be assumed to be recent. Trends in HIV prevalence among cohorts of conscripts were often considered as a proxy for trends in HIV incidence, the number or rate of new infections annually. However, most conscripts had lower social, economic and educational status compared to other groups, and tended to have higher rates of infection than the general male population.

**Figure 3. Prevalence of HIV infection among Thai military conscripts**

![Graph showing HIV prevalence among Thai military conscripts](image)

Source: Division of Epidemiology, Ministry of Public Health.

**Figure 4. HIV prevalence among women attending antenatal clinics in Thailand, 1990–1999**

![Graph showing HIV prevalence among women attending antenatal clinics](image)

Source: Division of Epidemiology, Ministry of Public Health.
The infection rate of pregnant women attending antenatal clinics increased from 0.7 per cent in 1991 to 2.3 per cent in 1995, before dropping to 1.8 per cent in 1996 and 1.5 per cent in 1998, and then increasing again to 1.74 per cent in 1999 (figure 4). These women gave birth to an estimated 4,000–6,000 HIV-infected children annually.

**Policy:** A greater understanding emerged that HIV was a social problem and deserved high priority at all levels. The NAC, chaired by the Prime Minister, emphasized the need for total cooperation among all sectors of society, so that both public and private sectors could play a constructive role in minimizing the impact of the disease.

**Organization structure:** Since six provinces in the upper northern region – Chiang Mai, Chiang Rai, Lampang, Payao, Lamphuon and Maehongson – had the largest number of HIV infections and patients with HIV-related illness in Thailand, the NAC established the Upper-North AIDS Administration Committee in 1994. This Committee was responsible for analysing budget disbursement, monitoring operational plans and preventing duplication among subcommittees, as well as helping the administrative committee to operate efficiently. Importantly, the Committee provided a means for more effective disbursement of funds to the community level, which opened channels for increased community involvement in the AIDS response.

**Programmes:** The four major programmes (from the 1992–1996 National AIDS Prevention and Control Plan) were: Public Information, Treatment and Care, Human Rights, and Research and Education. Since HIV was treated as a social problem, all parties concerned were encouraged to participate according to their particular areas of responsibility. The relevant budget was increased sixfold from 1991 to 1994 to a total of 1,142.5 million Baht.

As the HIV epidemic spread and changed rapidly in mid-decade, the prevention and control programmes were adjusted to emphasize changing high-risk behaviour and involve more agencies (table 1). The Government assigned more resources to HIV prevention. Activities were adopted nationwide in 1991 to promote universal use of condoms in commercial sex (Rojanapithakorn 1991). However, although the prevention portion of the budget increased from 9.3 per cent in 1995 to 14.3 per cent in 1996, about 65 per cent was devoted to treatment, because of the high unit cost. Included in unit costs are patient care, prevention of infection in hospitals and clinics, training of relevant health personnel, construction of HIV inpatient wards, etc. The budget also covered HIV-sentinel surveillance of risk groups and the provision of breastmilk substitutes to babies 0–2 years old whose mothers were HIV-positive.
Table 1. Policy plan/programme and budget of HIV prevention and control programme, 1995–1996

<table>
<thead>
<tr>
<th>Programme</th>
<th>1995</th>
<th>1996</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Million Baht</td>
<td>Million Baht</td>
</tr>
<tr>
<td>HIV and AIDS Behavioural and Social Prevention Programme</td>
<td>144.5</td>
<td>294.7</td>
</tr>
<tr>
<td>Health Promotion and Medical Treatment and Care Programme</td>
<td>1,019.3</td>
<td>1,350.9</td>
</tr>
<tr>
<td>Consultation Services Programme</td>
<td>20.0</td>
<td>33.0</td>
</tr>
<tr>
<td>Support and legal measures for people living with HIV</td>
<td>39.0</td>
<td>154.4</td>
</tr>
<tr>
<td>Research and Evaluation Programme</td>
<td>16.2</td>
<td>50.4</td>
</tr>
<tr>
<td>Management Development Programme</td>
<td>319.3</td>
<td>173.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1,558.4</strong></td>
<td><strong>2,057.1</strong></td>
</tr>
</tbody>
</table>

Source: Bureau of Budget, Ministry of Finance.

Phase III: Civil society focus 1997–2001

**Situation**: As indicated earlier, the 18th Round of HIV Serosurveillance in June 2000 showed that since the rate of transmission via commercial sex was only declining slowly, HIV infection was bound to spread to low-risk partners and children. The prevalence of HIV in pregnant women increased from the 1997 rate of 1.74 per cent to 2.02 per cent in 1999. There is now no region in Thailand where the infection rate among pregnant women is declining. The Thai Working Group on HIV/AIDS Projection (March 2001) indicated that approximately 4,000 Thai children were being infected with HIV annually. Research shows that without any medical intervention, roughly 25–35 per cent of HIV-positive pregnant women infect their newborn children during pregnancy, childbirth, or breastfeeding (Shaffer et al. 1999). However, a short course of AZT during pregnancy and labour can reduce the probability of HIV transmission from mother to child to about 8.2 per cent. Half of all children not treated would die by the age of five (Kanshana et al. 2000).

**Policy**: Government policy was reoriented to a more holistic approach. It was accepted that AIDS was not the sole responsibility of the Government, and that strengthening the role of all related actors according to their specific missions was essential for success. This included involving NGOs in public service, the private sector in prevention and control of the disease, and individual families and communities in activities such as home care programmes (National AIDS Prevention and Control Committee 1996). The National AIDS Foundation was established to campaign for funds to support the activities of NGOs, HIV infection groups and community organizations.
Organization structure: In 1997, two national committees were established under NAC. One was the AIDS Programme Executive Board, with four subcommittees: AIDS vaccine development; international cooperation on HIV and AIDS; problems of ARV procurement; and coordination between public and private care providers. The other national committee was the Management Committee for the Fight against HIV/AIDS in the Upper-North.

The NAC consisted of seven subcommittees: Public information on HIV control; research and education on HIV control; community involvement in HIV control; medical precautions necessary for HIV control; strengthening indigenous knowledge and wisdom and research for HIV control; and HIV prevention and control at the provincial level.

Programmes and projects: The National Prevention and Alleviation HIV/AIDS Plan (1997–2001) proposed eight comprehensive strategies to tackle the epidemic:

i) Developing the potential of individuals, families and communities to prevent and alleviate the onset of HIV while promoting a spirit of mutual assistance, and preserving the community culture.

ii) Strengthening business undertakings that are not destructive of Thai culture and traditions. This strategy included dissemination of good quality information and documentation via the mass media.

iii) Providing psychosocial support to enable people living with HIV to lead a normal life without any discrimination.

iv) Developing basic social services to promote a sound understanding of healthy behaviour; caring for affected people, including the elderly and children orphaned by AIDS; and improving the availability and quality of HIV counselling services by both the public and private sectors.

v) Introducing health promotion schemes and medical care services, emphasizing the provision of appropriate medical services for patients with HIV-related illness, and encouraging home care in the family and community.

vi) Utilizing cultural wisdom and available knowledge and promoting relevant research. This strategy emphasized the planning and conduct of further high-quality relevant research, promoting exchange of knowledge among researchers domestically and internationally, and developing industries essential for development and production of technologies necessary for HIV prevention and control.

vii) Enhancing international cooperation in assessing and exchanging HIV-related technologies and state-of-the-art techniques for prevention and alleviation of HIV problems.

viii) Revising and strengthening managerial processes in order to create a holistic approach to programme management from the national to the regional level.
From 1997 to 2001, the average budget for HIV and AIDS was 1.5 billion Baht per year (table 2).

Due to the financial crisis, the total funding for AIDS programmes declined by 9 per cent between 1996 and 1997 (from 2,187.5 million to 1,986.1 million Baht), and was then reduced even more dramatically, by 27.8 per cent, from 1997 to 1999. From 1997, prevention expenditure dropped by half and declined as a share of the total AIDS budget from 11 per cent to 8 per cent.

The main cut was in the budget for antiretroviral therapy, because there were doubts about the effectiveness of the therapy. Free condom distribution was also reduced, from 45 million to 12 million (1998 figure), in order to encourage cost sharing as much as to conserve the budget.

The main activities were: formulating the HIV plan and supporting NGOs and private activities; developing the potential of individuals and communities to prevent HIV and alleviate its effects; implementing the ‘100 per cent Condom Use Programme’; supporting care for children born of infected mothers, abandoned children and orphans; and job training and skill development for PLHIV and infected family members to allow them greater employment opportunities. Other important activities emphasized providing medical treatment to patients suffering from opportunistic HIV-related infections; safe donation and transfusion of blood; supporting antiretroviral therapy (ART); and providing free HIV testing to pregnant women. Those who were HIV-positive would receive a short regimen of AZT before and after delivery, AZT syrup for the child, and a year’s supply of breastmilk substitute (powdered milk).

In 1998 the Government shifted the budget for maintaining programme coverage for maternal and child health and HIV activities by:

i) protecting the budget for safe motherhood activities by keeping it at the FY 1997 level;

ii) allocating additional budget (estimated at 80 million Baht) to cover the higher cost of essential imported vaccines under the Extended Programme for Immunization; and

iii) restoring the HIV and AIDS budget to the FY 1997 level by allocating additional budget (estimated at 105 million Baht) for prevention, community development, and activities of NGOs.

During 2001 the budget allocated to support quality of life for HIV-infected persons was maintained at 2.2 per cent of the total health budget, or $33.8 million.
Table 2. Thai Government national AIDS programme budget 1997–2001 (millions of Baht)

<table>
<thead>
<tr>
<th>Programme components</th>
<th>1997 %</th>
<th>1998 %</th>
<th>1999 %</th>
<th>2000 %</th>
<th>2001 %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HIV prevention and mitigation programmes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1) Subprogramme on developing the capacity of individuals, families and communities</td>
<td>217.3</td>
<td>10.9</td>
<td>138.3</td>
<td>9.3</td>
<td>108.9</td>
</tr>
<tr>
<td>1.1) Strengthening community capacity to prevent and alleviate HIV</td>
<td>118.8</td>
<td>6.0</td>
<td>66.6</td>
<td>4.5</td>
<td>45.7</td>
</tr>
<tr>
<td>1.2) Strengthening learning processes and knowledge about preventing and alleviating HIV</td>
<td>98.5</td>
<td>5.0</td>
<td>71.6</td>
<td>4.8</td>
<td>63.2</td>
</tr>
<tr>
<td>2) Subprogramme on social and psychosocial services</td>
<td>85.2</td>
<td>4.3</td>
<td>102.1</td>
<td>6.9</td>
<td>89.5</td>
</tr>
<tr>
<td>2.1) Provision of welfare services to mitigate the impact of HIV</td>
<td>76.9</td>
<td>3.9</td>
<td>91.7</td>
<td>6.2</td>
<td>83.2</td>
</tr>
<tr>
<td>2.2) Developing and strengthening the economic status of infected individuals and families</td>
<td>6.0</td>
<td>0.3</td>
<td>8.1</td>
<td>0.5</td>
<td>4.7</td>
</tr>
<tr>
<td>2.3) Protection of human rights of infected people</td>
<td>2.3</td>
<td>0.1</td>
<td>2.3</td>
<td>0.2</td>
<td>1.6</td>
</tr>
<tr>
<td>3) Coordination of policy and HIV implementation programmes</td>
<td>213.8</td>
<td>10.8</td>
<td>141.6</td>
<td>9.6</td>
<td>136.5</td>
</tr>
<tr>
<td><strong>HIV prevention and control programmes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1) Subprogramme on health promotion and medical services</td>
<td>1,436.9</td>
<td>72.4</td>
<td>1,052.8</td>
<td>71.1</td>
<td>1,049.5</td>
</tr>
<tr>
<td>1.1) Health promotion for HIV prevention and control</td>
<td>57.5</td>
<td>2.9</td>
<td>72.0</td>
<td>4.9</td>
<td>144.3</td>
</tr>
<tr>
<td>1.2) Treatment and care services for infected people</td>
<td>972.4</td>
<td>49.0</td>
<td>894.9</td>
<td>60.4</td>
<td>892.8</td>
</tr>
<tr>
<td>1.3) Provision of support facilities for treatment and care</td>
<td>0.6</td>
<td>0.0</td>
<td>0.6</td>
<td>0.0</td>
<td>0.7</td>
</tr>
<tr>
<td>1.4) Pre and post counselling services</td>
<td>25.2</td>
<td>1.3</td>
<td>11.6</td>
<td>0.8</td>
<td>11.8</td>
</tr>
<tr>
<td>1.5) Homes for HIV patients</td>
<td>381.1</td>
<td>19.2</td>
<td>73.7</td>
<td>5.0</td>
<td>-</td>
</tr>
<tr>
<td>2) Subprogramme on developing the wisdom of the people and research studies</td>
<td>32.9</td>
<td>1.7</td>
<td>46.7</td>
<td>3.2</td>
<td>54.6</td>
</tr>
<tr>
<td>2.1) Development of the people’s wisdom and researches on the HIV problem</td>
<td>32.9</td>
<td>1.7</td>
<td>46.7</td>
<td>3.2</td>
<td>54.6</td>
</tr>
<tr>
<td>2.2) Research and development on AIDS vaccine</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1,986.0</td>
<td>100</td>
<td>1,481.5</td>
<td>100</td>
<td>1,439.0</td>
</tr>
</tbody>
</table>

Source: Bureau of the Budget.
Note: Figures for 1997–1999 are actual expenditure; figures for 2000–2001 are budgeted.
Table 3. Thai Government national AIDS programme budget 2002–2005 (millions of Baht)

<table>
<thead>
<tr>
<th>Programme components</th>
<th>2002*</th>
<th>%</th>
<th>2003</th>
<th>%</th>
<th>2004</th>
<th>%</th>
<th>2005</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV mitigation programmes</td>
<td>864.8</td>
<td>87.10</td>
<td>917.97</td>
<td>74.72</td>
<td>1,335.57</td>
<td>81.02</td>
<td>1,337.19</td>
<td>82.97</td>
</tr>
<tr>
<td>Development of the people’s wisdom and researches on the HIV problem</td>
<td>41.24</td>
<td>4.15</td>
<td>61.04</td>
<td>4.97</td>
<td>70.98</td>
<td>4.31</td>
<td>56.29</td>
<td>3.49</td>
</tr>
<tr>
<td>Research and development on AIDS vaccine</td>
<td>1.56</td>
<td>0.16</td>
<td>3.00</td>
<td>0.24</td>
<td>2.65</td>
<td>0.16</td>
<td>2.28</td>
<td>0.14</td>
</tr>
<tr>
<td>Welfare project to enable HIV patients to return home</td>
<td>36</td>
<td>2.93</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>992.83</strong></td>
<td><strong>100.00</strong></td>
<td><strong>1,228.59</strong></td>
<td><strong>100.00</strong></td>
<td><strong>1,648.45</strong></td>
<td><strong>100.00</strong></td>
<td><strong>1,611.67</strong></td>
<td><strong>100.00</strong></td>
</tr>
</tbody>
</table>

Note: Does not include the 480.06 million Baht health service budget.

Table 4. Summary of the evolution of HIV and AIDS in Thailand

<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Organization management</td>
<td>Health Focus</td>
<td>Social Focus</td>
<td>Civil Society Focus</td>
</tr>
<tr>
<td>Committee (National level since 1990, Minister as a chair)</td>
<td>National Committee (chaired by Prime Minister)</td>
<td>National Committee (chaired by Prime Minister)</td>
<td></td>
</tr>
<tr>
<td>Situation</td>
<td>Total AIDS cases (cumulative)</td>
<td>268</td>
<td>68,419</td>
</tr>
<tr>
<td>Male</td>
<td>236 (88%)</td>
<td>56,060 (82%)</td>
<td>183,660 (71.96%)</td>
</tr>
<tr>
<td>Female</td>
<td>32 (12%)</td>
<td>12,359 (18%)</td>
<td>71,577 (28.04%)</td>
</tr>
<tr>
<td>Ratio male to female</td>
<td>7.4 : 1</td>
<td>4.5 : 1</td>
<td>2.57 : 1</td>
</tr>
<tr>
<td>Deaths (cases)</td>
<td>139</td>
<td>20,186</td>
<td>72,183</td>
</tr>
<tr>
<td>Children 0–14 years old infected</td>
<td>22</td>
<td>3,682</td>
<td>10,991</td>
</tr>
<tr>
<td>Male</td>
<td>14 (64%)</td>
<td>1,972 (54%)</td>
<td>5,771 (52.51%)</td>
</tr>
<tr>
<td>Female</td>
<td>8 (36%)</td>
<td>1,710 (46%)</td>
<td>5,220 (47.49%)</td>
</tr>
<tr>
<td>Highest risk behaviour</td>
<td>sexual transmission (73%)</td>
<td>sexual transmission (81%)</td>
<td>sexual transmission (83.71%) (remainder included 4.74% IDU; 4.19% MTCT)</td>
</tr>
<tr>
<td>Province with most AIDS cases</td>
<td>Chiang Mai</td>
<td>Chiang Mai</td>
<td>Chiang Mai</td>
</tr>
</tbody>
</table>

Source: Division of Epidemiology, Ministry of Public Health, October 2004.
Long-term socioeconomic impacts of HIV on children

Psychosocial distress

Infected children tend to develop ‘emotional deprivation’, as they are generally depressed and live in conditions that are both physically and mentally unhealthy. Children who are not infected themselves but live with infected parents often feel lonely and develop a sense of grievance about their parents’ illnesses.

Schools play a significant role in children’s socioemotional development, but instead of experiencing positive socialization, children affected or infected by HIV feel they are in an uncaring and unsupportive environment. They are frequently stigmatized, rejected and socially isolated from their peers, which drives them to depression, withdrawal and prolonged absence from school. Little effort is made to enhance schools’ ability to provide support to children in general, and specifically to children from families affected by HIV.

There is at present no direct evidence or research to indicate precisely how many children there are or will be in such circumstances. However, there are clear implications that the long-term impact on a number of abandoned children and orphans, as well as many HIV-infected children, will be severe.

Impacts on pregnant women and infected mothers

The prospect of HIV transmission from mother to child causes great physical and mental suffering for mothers. They may feel hopeless and depressed and thus fail to provide appropriate care for their children (Limroungrong 1997). Additional problems for the mother include providing for the child while she herself is sick, or after she dies, the relationship with the husband and his ability or willingness to provide for the family.

Abandoned children and homelessness

HIV-infected women tend to abandon their babies because they are unprepared to take care of a child with a high probability of infection, and fear being stigmatized by their families and the community if the baby is HIV-positive. Babies born to infected mothers are more than five times as likely to be abandoned as those whose mothers are not infected (table 5). A study of one hospital from 1992 to 1994 showed that an average of 3.16 per 1,000 babies born to infected mothers were left behind in the hospital, whereas the rate for uninfected mothers was 0.59 per 1,000.
As the Department of Communicable Disease Control indicates that the number of HIV-infected pregnant women has increased over time, the problem of orphans and abandoned children can be expected to worsen and the need for effective programmes to curb the spread of the HIV epidemic among those of reproductive age will be even more urgent. However, due to the economic crisis in 1997, the AIDS programme budget has been reduced (tables 2 and 3), and this has exacerbated the situation.

**Children orphaned by AIDS**

Most children orphaned by AIDS are born before their parents are infected. One 1994 study showed that many children 5–12 years old with infected mothers would be orphaned within two years.

**Table 6. Estimates of numbers of Thai children likely to be orphaned by AIDS (in ’000s)**

<table>
<thead>
<tr>
<th>Year</th>
<th>Total no. of children 0–14 years</th>
<th>Total no. of orphans</th>
<th>Total no. of orphans due to AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>16,828</td>
<td>904</td>
<td>63</td>
</tr>
<tr>
<td>2001</td>
<td>16,752</td>
<td>1,048</td>
<td>289</td>
</tr>
<tr>
<td>2005</td>
<td>16,787</td>
<td>1,094</td>
<td>380</td>
</tr>
<tr>
<td>2010</td>
<td>16,635</td>
<td>1,054</td>
<td>374</td>
</tr>
</tbody>
</table>


These orphans can have a difficult time adapting to life with relatives or in an orphanage, and with an uncertain future can easily become involved in crime, drugs or sex work.

**Changes in household and family structure**

In the medium term, the HIV epidemic will change family structures. Without ARV treatment, HIV-positive adults live for five to 10 years after becoming infected, and have a two- to three-year life expectation after developing AIDS. Since more males than females are infected, many families are likely to be without their male breadwinner.
Women, as mothers and family caretakers, will have to work harder while facing greater stresses. For those women who are HIV infected, there is a high risk of their children being neglected or orphaned and having to be left in the care of the elderly, other relatives or the community.

Social capital and civil society

Since 1991, campaigns to reduce fear of the infected and discriminatory attitudes against those susceptible to the disease have been carried out nationwide. Levels of acceptance vary. In some communities, there is considerable discrimination, but in others, affected and infected persons receive support, encouragement and sympathy from their neighbours and communities. Some communities establish a saving fund where part of the fund is set aside to provide welfare to the members, in such forms as cash transfers, or cremation expenses. One of the cornerstones of Thailand’s response to the HIV epidemic has been the involvement of community organizations, in particular the formation of self-help groups by people living with HIV. Since the formation of the first group in 1993 there are now over 770 such groups in the country. The self-help groups have also developed strong networks at the regional and national level, which have been a powerful force in national policy formation and have helped advocate for their rights and more effective allocation of resources. Faith leaders have also taken part in helping HIV-affected and infected persons. Some institutions, such as the Buddhist temple, Thammarak Nives, have provided hospice support for people dying of HIV-related illnesses. Through projects such as the UNICEF-supported Sangha Metta Project in Chiang Mai, monks have been trained in HIV awareness to enable them to undertake prevention and care work in their own communities.

The Rights of the Child

Education: The Constitution of the Kingdom of Thailand recognizes that all children have the right to be protected and receive basic social services. In addition, under the National Education Act B.E. 2542 (1999), all children have the right to nine years of free education. In practice, however, HIV-affected children’s right to education is violated both by the community and the schools. Communities continue to believe that if parents have HIV infection, then their children must also be infected. Non-HIV-affected parents try to prevent children whose parents are infected from attending school with their own children or dependants. Some schools, citing potential health problems, persuade, or even force, the parents or guardians of affected children to take them out of school. Moreover, there is frequently pressure to force children to take a blood test before they enrol in school.

Children from households, particularly poor ones, where someone has died of an HIV-related illness, are taken out of school to work, help with household chores, or take care of younger children and the sick person (Pitayanon, Kongsin and Janjaroen 1997; Janjaroen 1996; Brown and Sittitrai 1996).
Right to receive standard health care: According to the Convention on the Rights of the Child, which has been ratified by Thailand, all children have the right to health care and neither health care providers nor hospitals should refuse treatment. In the early stage of the epidemic, such discrimination did occur, but as societal understanding has increased, the situation has improved.

Policy response to HIV in Children

HIV prevention programmes

Major strategies and approaches for preventing new HIV infections include the following:

Strengthening health education: Promotion of health education has evolved over time; once the sole responsibility of the Government, now a wide variety of agencies have been encouraged to play their part.

NGOs: There are over 1,000 NGOs and more than 770 self-help groups of people living with HIV (MoPH, AIDS Division 1998a). The activities of these groups complement public sector work on HIV, especially among fishermen, migrants and minorities in remote areas. NGO activities tend to be more flexible than those of the public sector, especially among high-risk groups, which require more time and two-way communication before any effort can be expected to lead to changes in sexual behaviour.

The Government began allocating funds to support NGOs in HIV prevention activities in 1992 and from 1997 to 2001 these funds averaged an annual 80 million Baht, or approximately 5 per cent of the total AIDS budget. During 2000–2001 loans of 90 million Baht were made under the Social Investment Project (SIP) to support NGOs in AIDS prevention activities.

Private business: Large private businesses provide training for their employees on HIV and AIDS. In 1993, the Thailand Business Coalition on AIDS was initiated to help businesses disseminate knowledge on HIV prevention more efficiently and effectively.

Community: Communities network with both NGOs and public agencies. They have a high capacity to promote activities that generate close relationships and ties among their members. They can also promote appropriate values to control risky situations, i.e. child prostitution and the luring of young persons into the sex service business. Communities may encourage volunteer groups to care for people living with HIV and affected children and provide support or motivate community leaders to initiate group interactions – such as that between mothers’ groups and youth groups.

HIV-infected people: Members of the 770 groups of people living with HIV not only provide moral support and consultation to other members, but also disseminate knowledge about the disease to those who have direct and indirect contact with
people living with HIV, thereby creating a better understanding of the disease and potentially leading to concrete changes in sexual behaviour.

**HIV surveillance**

HIV surveillance was first implemented in Thailand in June 1989 in 14 provinces and extended to cover the whole country the following year. The major task of this project was to follow up and monitor the HIV epidemic in seven groups considered at risk: blood donors; injecting drug users; pregnant women; males visiting STI clinics; SWs, both male and female; fishermen; and foreign labourers.

During the first wave of the epidemic, HIV testing was conducted in two rounds each year in June and December. After 1995 the new infection rate in risk groups stabilized and HIV testing was conducted once a year in June.

**Promotion of condom use**

A major method of preventing HIV transmission is use of condoms, since more than 80 per cent of HIV transmission is via sexual relations. The 100 per cent condom use programme was initiated in 1989 and aimed at males who visited SWs, and other members of high-risk groups. In August 1991, NAC broadened coverage to every province in Thailand. The Government allocated a budget for condom distribution, but because of the economic crisis, it was cut from 70 million Baht in 1996 to 29 million Baht in 1997 and then slightly increased to 40 million Baht in 2001.

Condoms were also available from independently funded STI clinics and countrywide distribution networks where the quality of the condoms was accredited by the Quality Control Law. SWs regularly received condoms free of charge, and were provided with health check-ups and sexual disease treatment every one or two weeks. Due to the general use of condoms, health personnel were usually able to trace the source of an HIV infection to failure to use a condom.

Cooperation between the public sector, the private sector and businesses has contributed to the high rate of condom use. Information retrieved from SWs by the Department of Communicable Disease Control showed that the rate of condom use increased from 25 per cent in June 1989 to 99 per cent in June 2001. This contributed to the decrease in STI disease and HIV prevalence among conscripts in May 2000, which declined to 1.4 per cent from a high of 4 per cent in 1993 (HIV Surveillance, Division of Epidemiology, MoPH).

**Prevention and treatment of STIs**

Sexually transmitted infections increase vulnerability to HIV infection and accelerate the onset of AIDS. Prevention and treatment of STIs should reduce new HIV infection by up to 40 per cent (Grosskurth and Waweret 1998). Prevention and control programmes were adopted that emphasized safe sex. Strategies included disseminating and exchanging information on HIV and health, promoting 100 per cent
condom use, surveillance of SWs, and encouraging activities carried out by the Friend-Help-Friend group, as well as providing appropriate pre- and post-consultation to vulnerable people.

Integrated HIV work included normal health services, e.g. family planning programmes, mothers’ hygiene and child programmes and extending the STI clinics to every district of the country. These measures have had a positive impact on the STI situation. There has been an improving trend, particularly after 1986, with the STI incident rate (cases per 1,000 population) dropping from 7.85 in 1986 to 0.25 in 2000 (MoPH 2001b).

Treatment and care for people living with HIV

The First National HIV/AIDS Plan (1992–1996) recognized that HIV would strain the capacity of the health system. In the beginning, only a few general hospitals, and even fewer community hospitals, were ready or willing to provide the range of services needed for HIV-positive patients. Therefore, the strategy was to strengthen both institutional and non-institutional treatment and care for people living with HIV. This meant ensuring the safety of the blood supply, improving capacity for diagnosis and treatment, establishing counselling services, ensuring universal precaution practices, training health personnel, and supporting family-and community-based treatment and care. The policy also emphasized cost-effective drug procurement measures, such as bulk purchase of generic drugs and contracts with pharmaceutical companies.

As the epidemic spread geographically and the incidence rate rose, particularly in the six upper northern provinces, it was realized that additional measures were needed. The Operation Plan for 1995–1996 aimed to further increase the capacity of the health service system and facilities to provide treatment for HIV or other opportunistic diseases, as well as to strengthen the referral system among government hospitals, and between government and private hospitals. Support was given to health personnel suffering from stress and fatigue in areas of high prevalence by instituting a rotation policy and encouraging staff to move in and out of the hard-hit areas. In addition, various temporary measures were introduced, such as extra remuneration for emergencies. One of the aims of the Plan was to facilitate families’ and communities’ capacity to provide health care for people living with HIV by integrating care for other chronic diseases in the community, but the policy was not implemented. Strategies that did help families included the community day-care system for patients with HIV-related illness set up by some community hospitals, whereby relatives or family members could carry on with their usual work while the patients awaited appointments with doctors.

Antiretroviral therapy

In 1992 the Department of Communicable Disease Control began a programme to supply ARV free of charge to 350 people living with AIDS (PWA). Though this number was approximately one fifth of the total reported number of eligible
patients, it was probably only 3 per cent of the actual total. Table 7 shows the number of PWA and people living with HIV (PWH) who received ARV each year. The number of recipients more than doubled from 1994 to 1995, although the total cost only increased by $5.39 million, due to the use of generic substitutes at less than $0.50 a tablet, rather than the $2.00 per tablet for non-generic drugs.

Table 7. Numbers of people living with HIV and AIDS and receiving antiretroviral therapy

<table>
<thead>
<tr>
<th>Year</th>
<th>No. of PWA at end of year</th>
<th>No. of PWH at end of year</th>
<th>No. of Reported PWA</th>
<th>No. of PWA receiving ARV from public finance</th>
<th>PWA receiving publicly financed ARV as % of reported PWA</th>
<th>PWA receiving publicly financed ARV as % of no. of PWA at end of year</th>
<th>Public spending on ARV including medical materials (in $ millions)</th>
<th>Total public spending on AIDS programme (in $ millions)</th>
<th>Estimated financial requirement to provide ARV for all PWA, as % of AIDS programme</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td>11,202</td>
<td>547,227</td>
<td>1,761</td>
<td>350</td>
<td>19.88</td>
<td>3.12</td>
<td>1.44</td>
<td>25.10</td>
<td>184.19</td>
</tr>
<tr>
<td>1993</td>
<td>20,195</td>
<td>640,356</td>
<td>6,900</td>
<td>700</td>
<td>10.14</td>
<td>3.47</td>
<td>3.45</td>
<td>58.32</td>
<td>170.78</td>
</tr>
<tr>
<td>1994</td>
<td>31,002</td>
<td>701,566</td>
<td>13,855</td>
<td>1,752</td>
<td>12.65</td>
<td>5.65</td>
<td>13.97</td>
<td>54.17</td>
<td>456.40</td>
</tr>
<tr>
<td>1995</td>
<td>41,863</td>
<td>736,992</td>
<td>20,604</td>
<td>3,600</td>
<td>17.47</td>
<td>8.60</td>
<td>19.36</td>
<td>65.55</td>
<td>343.41</td>
</tr>
<tr>
<td>1996</td>
<td>51,712</td>
<td>751,522</td>
<td>24,478</td>
<td>2,200</td>
<td>8.99</td>
<td>4.25</td>
<td>15.84</td>
<td>86.33</td>
<td>431.22</td>
</tr>
<tr>
<td>1997</td>
<td>59,752</td>
<td>751,235</td>
<td>26,342</td>
<td>2,200</td>
<td>8.35</td>
<td>3.68</td>
<td>11.74</td>
<td>63.31</td>
<td>503.82</td>
</tr>
<tr>
<td>1998</td>
<td>65,333</td>
<td>740,349</td>
<td>26,410</td>
<td>2,200</td>
<td>8.33</td>
<td>3.37</td>
<td>8.68</td>
<td>35.81</td>
<td>719.46</td>
</tr>
<tr>
<td>1999</td>
<td>68,311</td>
<td>719,765</td>
<td>22,267</td>
<td>2,200</td>
<td>9.88</td>
<td>3.22</td>
<td>8.51</td>
<td>40.07</td>
<td>659.68</td>
</tr>
<tr>
<td>2000</td>
<td>68,677</td>
<td>694,564</td>
<td>12,8391</td>
<td>2,100</td>
<td>17.131</td>
<td>3.13</td>
<td>7.07</td>
<td>35.40</td>
<td>623.65</td>
</tr>
<tr>
<td>2001</td>
<td>67,057</td>
<td>665,344</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>33.87</td>
<td>622.22</td>
</tr>
</tbody>
</table>

Sources: (a) The Thai Working Group on HIV/AIDS Projection, 2001, Table B1i, p B-11; (b) Epidemiology Division, MoPH, Reported AIDS Situation, various years; (c) Bureau of Budget, Office of Prime Minister, Budget Document of MoPH, various years.

Notes: (1) Reported cases as of October 2000; (2) As indicated in the budget document in the corresponding year; (3) Calculation assumed the same treatment regimen as publicly funded programme.
As the 50 per cent of the national AIDS programme budget spent for procuring antiretroviral drugs and drugs to treat opportunistic infections was disproportionately larger than the amount allocated for care of other diseases, this policy had to be reconsidered in terms of equitable distribution of resources among disadvantaged groups.3

In late 1995, NAC received support from WHO to conduct a cost-effectiveness study on the use of ARV to treat HIV.4 The study observed low compliance with medication regimens, due to patients’ aversion to side effects and lack of follow-up by physicians. It also found that the number of programme beneficiaries was too low, that a full-scale treatment regimen was unaffordable, and that the clinical effectiveness of mono-therapy was limited as it only extended survival up to six months. Following the study, the Government modified its policy and abandoned mono-therapy in favour of combination therapy.

With recent reductions in the price of the drugs and increased external support, the possibility of providing ARV treatment to all patients with HIV-related illness has improved markedly. On World AIDS Day 2003, WHO and UNAIDS set the global target of treating 3 million PWA with ARV by 2005. Thailand has joined the initiative and the Government allocated a budget of $7.7 million for 2003, which was almost tripled to $20.5 million for 2004. The programme was rolled out to 914 hospitals nationwide in three years and increased at the rate of 3,000 new adult patients a month between January and August 2004. By December 2004 it was estimated that at least 45,000 PWA were being treated with ARV – some 44 per cent of the estimated 114,000 PWA 15–49 years old who actually needed the therapy (UNAIDS and WHO 2004).

Treatment and care for mothers and children living with HIV

Thailand is one of the few countries that also focuses on treating children infected with HIV. Under the national programme, 200–300 children were being enrolled every month from January to August 2004. They constitute about 8 per cent of the total number of patients (UNAIDS 2004). But for children, the main emphasis is on preventing them ever being infected. Comprehensive measures were initiated to prevent vertical transmission of HIV in the late 1980s and early 1990s. Interventions included massive health and sex education campaigns among children and young people starting from grades 5 or 6, premarital counselling, and voluntary anonymous testing for HIV.

Surveillance of HIV-infected women from 1989 to 2000 showed that the infection rate of pregnant women increased from 0.8 per cent in 1990 to 1.76 per cent in 1999. Since the results of a research study conducted by a team of US physicians indicate that the HIV transmission rate from mother to child is 30 per cent without
treatment, 4,000–5,000 Thai babies are likely to be infected annually. The Thai Red Cross claimed that the transmission rate could be reduced to 8 per cent if mothers were to receive AZT before delivery and during labour, and newborns were to be given AZT for the first six weeks of life.

In 1997, the Ministry of Public Health started a programme to give AZT to infected pregnant women and supply powdered milk to children infected by their mothers for one year. In March 1998, a CDC and MoPH-supported trial in Bangkok showed that short-course AZT could reduce mother–infant HIV transmission by 50 per cent among non-breastfeeding HIV-infected women.

Guidelines for implementation of PMTCT in Thailand

1. All service-providing institutions must organize HIV testing and high-quality confidential counselling services for couples. Only the pregnant woman and those to whom she has given permission are authorized to receive the test results.

2. All pregnant women should be offered voluntary testing for HIV antibodies according to the standards set by the MoPH.

3. All HIV-infected pregnant women who decide to continue their pregnancy will be offered AZT as follows:

4. Starting at 34 weeks of pregnancy, morning and evening, with each dose totalling 300 mg until labour pains commence.

5. During labour, the dose provided will be 300 mg every three hours until delivery.

6. For babies born to HIV-infected mothers:

7. All babies of HIV-infected mothers who have taken antiretroviral drugs for four weeks or more during pregnancy and delivery will get AZT syrup, starting immediately after birth at a dose of 2 mg per 1 kg body weight every six hours for seven days.

8. All babies of HIV-infected mothers who have taken antiretroviral drugs for less than four weeks during pregnancy and delivery will get AZT syrup, starting immediately after birth at a dose of 2 mg per 1 kg body weight every six hours for six weeks.

9. All babies born to HIV-infected mothers will receive infant formula to substitute breastfeeding until 12 months of age.

10. All babies born to HIV-infected mothers will get a blood test for HIV antibodies at 12 months of age. If the result is positive, the babies will be retested at 18 months of age.

11. All mothers and infants who receive antiretroviral drugs will receive proper medical care and treatment.
The 1998–2000 report of the PMTCT programme implementation in regions 1, 2, 3, 6, 7 and 12 indicated that, out of the total 27,401 women who delivered at public hospitals under the supervision of MoPH, 98 per cent attended antenatal clinics and 75 per cent agreed to have their blood tested for HIV; 64 per cent of the HIV-positive women who came for delivery received AZT.

Before the ACT076 treatment regime was proven effective, infant formula was provided to babies for a period of two years in order to prevent HIV transmission through breastmilk. This was later modified to a period of one year. Difficulties arose when the paediatric wards administered different feeding practices. When mothers and babies were discharged from the hospital, they were supplied with infant formula to last until their next appointment, but in most cases the mothers did not return.

Table 8 shows the number of children born to HIV-positive women who received powdered milk and AZT as well as financial assistance. However, it should be noted that this treatment was only provided during pregnancy, labour and for a short period after delivery. It was not extended to cover the whole life span of the mothers with HIV.

### Table 8. Burden of care for pregnant women and children with HIV

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No. of children 0–2 years</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>born to HIV-positive mothers who received milk substitutes</td>
<td>1,000</td>
<td>1,000</td>
<td>2,000</td>
<td>2,381</td>
<td>3,108</td>
<td>3,210</td>
<td>7,147</td>
<td>7,500</td>
<td>9,700</td>
</tr>
<tr>
<td><strong>No. of children born to HIV-positive mothers who received ARV</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Estimated public expenditure on powdered milk for children 0–2 years born to mothers with HIV (in $ millions)</strong></td>
<td>0.37</td>
<td>0.88</td>
<td>0.82</td>
<td>0.79</td>
<td>0.86</td>
<td>0.73</td>
<td>2.12</td>
<td>2.02</td>
<td>1.44</td>
</tr>
<tr>
<td><strong>Estimated public expenditure on ARV for children and mothers (in $ millions)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Bureau of the Budget, Office of the Prime Minister, Budget Document of MoPH, various years.

Note: Figures in parentheses denote numbers of children 13–24 months old.
In 2002 the Government began providing combination therapeutic treatment to about 500 HIV-positive mothers. This was only 5 per cent of those who initially received treatment to prevent HIV transmission to their newborn babies. However, the Minister of Public Health then announced that by 2005 ARV treatment would be available to all those who needed it.

Policy/programme measures for mitigation of the impact of HIV

In 1999, the HIV infection rate decreased by 24.5 per cent. However, the epidemic continues to spread throughout the country, especially in the north (tables 9 and 10).

Table 9. Comparison of reported HIV patients and HIV-related cases in the upper northern part of Thailand and the whole country

<table>
<thead>
<tr>
<th>Year</th>
<th>Upper north region (Region 10)</th>
<th>Whole country 12 regions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of people</td>
<td>% of total</td>
</tr>
<tr>
<td>1984–1989</td>
<td>29</td>
<td>9.73</td>
</tr>
<tr>
<td>1990</td>
<td>92</td>
<td>20.81</td>
</tr>
<tr>
<td>1991</td>
<td>472</td>
<td>42.48</td>
</tr>
<tr>
<td>1992</td>
<td>1,499</td>
<td>48.37</td>
</tr>
<tr>
<td>1993</td>
<td>4,336</td>
<td>48.03</td>
</tr>
<tr>
<td>1994</td>
<td>7,496</td>
<td>39.63</td>
</tr>
<tr>
<td>1995</td>
<td>9,425</td>
<td>32.65</td>
</tr>
<tr>
<td>1996</td>
<td>9,777</td>
<td>28.37</td>
</tr>
<tr>
<td>1997</td>
<td>9,911</td>
<td>26.59</td>
</tr>
<tr>
<td>1998</td>
<td>8,896</td>
<td>23.67</td>
</tr>
<tr>
<td>1999</td>
<td>7,786</td>
<td>21.40</td>
</tr>
<tr>
<td>2000</td>
<td>6,966</td>
<td>19.97</td>
</tr>
<tr>
<td>2001</td>
<td>6,316</td>
<td>19.19</td>
</tr>
<tr>
<td>2002</td>
<td>5,174</td>
<td>16.33</td>
</tr>
<tr>
<td>2003</td>
<td>4,860</td>
<td>17.24</td>
</tr>
<tr>
<td>2004</td>
<td>3,044</td>
<td>22.63</td>
</tr>
<tr>
<td>Total</td>
<td>86,080</td>
<td>24.69</td>
</tr>
</tbody>
</table>

Source: Office of Communicable Disease Control, Region 10, Chiang Mai.
Note: Data until November 2004.
Table 10. HIV transmission route among various groups in the upper north and whole country

<table>
<thead>
<tr>
<th>Groups of people</th>
<th>Upper north (region 10)</th>
<th>Whole country (12 regions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood donation</td>
<td>0.82</td>
<td>0.57</td>
</tr>
<tr>
<td>Intravenous drug users</td>
<td>46.64</td>
<td>40.00</td>
</tr>
<tr>
<td>Pregnant women</td>
<td>5.00</td>
<td>1.68</td>
</tr>
<tr>
<td>Male patients at STI clinics</td>
<td>18.81</td>
<td>6.79</td>
</tr>
<tr>
<td>Brothel-based SWs</td>
<td>57.14</td>
<td>26.14</td>
</tr>
<tr>
<td>SWs not in brothels</td>
<td>13.74</td>
<td>8.20</td>
</tr>
</tbody>
</table>

Source: Division of Epidemiology, Ministry of Public Health.
Note: Surveillance data from specific areas in June 1997.

Provision of social services to HIV-positive people, patients with HIV-related illness and their families

Provision of social services commonly includes consultation, supplying milk substitutes, home visiting, financial assistance to families, career training, funds for education, friends-help-friends groups, the hotline service, and anonymous consulting units.

The Government provides free breastmilk substitutes for HIV-positive mothers, and free school lunch programmes for eligible primary school students. Both programmes have been expanded since the financial crisis of 1997. The priority target group is poor and disadvantaged children: prior to the crisis, 30 per cent of all children were eligible for the free lunch programme but currently 50 per cent are eligible. However, there is no guarantee that all infected and affected children do in fact receive the benefits available.

After the 1997 economic crisis, cash transfers for the elderly increased from 200 to 300 Baht per month/person. By 1999, the number of the elderly eligible for such transfers had also increased from 300,000 to 400,000 persons. However, there are still a large number of the elderly who are not covered by this programme.

Cooperation among agencies and effective management

NGO partnerships with the Government have had a major impact on community development and mobilization (World Bank 2000b), and their links with the private sector are more flexible in approaching and helping targeted vulnerable groups that are HIV-infected and poor. There have been increasing efforts to coordinate initiatives among the NGO community and build partnerships through greater networking (e.g. NGO Coalition on AIDS and National Council for Social Welfare). Greater cooperation among the many sectors and provincial administrations is also a major goal.
During the economic crisis, the Ministry of Public Health was allocated a 90 million Baht loan from the World Bank to support HIV prevention and control programmes. The Government selected development agencies as partners for the following activities:

i) cooperation with local agencies to support local planning activities;

ii) development of effective prevention and care programmes;

iii) technological and technical transfer to local organizations;

iv) collaboration among networks of private NGOs working on HIV problems in other regions;

v) monitoring and follow-up to support effective programmes and ensure their sustainability.

The role of social capital and local organizations in assisting HIV-infected persons

After the 1997 economic crisis, the Thai Government assigned a portion of its World Bank loan to social investment through community development. The $120-million social investment fund (SIF) was created for local and community grassroots organizations to implement their development projects. The funds were channelled through the Social Fund Office of the Government Savings Bank. The Office granted money for projects initiated by local community organizations, municipalities and other informal groups, the general purpose being to promote civil society and strengthen good governance throughout the country at all levels of administration.

One of the five SIF classifications was ‘Community welfare and safety’ programmes initiated by the communities themselves, such as child development and day-care centres, community playgrounds, and shelters for the elderly and patients with HIV-related illness. Since the beginning of September 1998, SIF has supported 3,131 such projects worth 352.27 million Baht.

More recently implemented were several government policies aimed at encouraging self-reliance and strengthening local people’s potential to help each other. The most well known are the ‘1-million-baht per village revolving fund’ and the ‘one village, one product scheme’. Both programmes aim to increase the local communities’ capability to generate income. Income gained from the programmes’ products is used to pay back the revolving fund, compensate producers and contribute to savings for the community’s welfare. Such savings will augment the increase in saving groups fostered under the Community Development Department, and will play an important future role in assisting and caring for those in need, including HIV-infected people. The majority of people infected with HIV end their lives at home and are therefore cared for by family members and supported by the communities.
In many areas across the country, Buddhist and Christian clergy offer a number of community-based programmes, including counselling, outreach and hospice services. The Sangha Metta Project in Chiang Mai trains monks in community-based HIV prevention and care (World Bank 2000b). Such programmes have significant power to combat stigmatization by associating patients with revered faith-based institutions.

**Conclusion and recommendations**

From 1984 until 31 June 2001, there were 172,760 cases of HIV, of whom 47,798 died. The percentage of males infected by using non-sterile needles greatly increased from 5 per cent in 1990 to 18 per cent in 2000 and is expected to rise to 30 per cent by 2005. Meanwhile, the percentage of females infected by their husbands or other sex partners is projected to decrease from 42 per cent in 2000 to 29 per cent in 2005.

The number of children orphaned by AIDS increased, from 63,000 in 1997 to 289,000 in 2001 and was expected to reach 374,000 by 2010 (UNAIDS, UNICEF and USAID 2002). These children, and mothers and children living with HIV, will place increasing demands on the economy for care and social support and will require policy responses in the area of prevention, treatment and mitigation.

Although Thailand has been successful in HIV-prevention efforts, there is a need to increase participation by communities, people living with HIV and other groups of people affected. In general, NGO–Government partnerships have worked best at the local level, through development of appropriate linkages between programmes and services.

**Lessons learned**

The evolution of Thailand’s AIDS policy and the impact of the programmes in reducing HIV problems suggest important lessons that may be of use for other countries in the region and the world:

i) **For action to be effective, national leadership and political commitment at the highest levels are required:** Leadership must recognize the devastating scale of the epidemic and be willing to discuss openly the enormity of the HIV problem. In Thailand, leaders with commitment to the most progressive HIV policies established the NAC, which serves as a policy decision body and includes members of government authorities, NGOs, business, community leaders and people living with HIV. The Government also committed adequate resources in the struggle against the epidemic.

ii) **Deployment of social capital and involvement of civil society:** In Thailand, actors include the public and private sectors, NGOs, families, communities,
and particularly civil society and faith-based groups. The Government has encouraged local people to form such groups by providing financial and technical support.

iii) **Effective programmes ‘lead’ policy to the right outcomes:** In Thailand, good policy arose from the examples of good programmes. The pilot programmes are likely to have the largest influence on policy when the impact is well documented. Factors contributing to success included a clear policy objective, strong political commitment from the central, provincial and local levels in providing technical advice and intensive public relation campaigns. Decision-making on allocation of resources and coordination was also decentralized, thus facilitating timely and effective response to local conditions. The involvement of small groups of core actors, with clear roles and responsibilities at the provincial level, helps minimize the duplication of activities and resources.

**Recommendations**

i) **Continue prevention programmes** by focusing more on target groups, such as the highest risk teens, MTCT and IDUs.

ii) **Develop a specific policy to assist boys and girls orphaned by AIDS.** Strengthen the capacity of the Government, families and communities to provide a supportive environment for affected and infected children through appropriate counselling and psychosocial support. There should also be a national policy and strategy to ensure non-discrimination and full and equal enjoyment of all human rights.

iii) **Enhance the roles of local authorities and communities.** Strengthen the potential and promote the role of affected groups, community-based organizations and NGOs so as to provide care for people living with HIV and their families. Improve and mobilize existing local funds and social capital from all sectors to help in this effort.

iv) **Develop counselling and mental care services** corresponding to the specific problems of the target groups. This includes providing professional counselling on a regular basis and providing counselling training to government personnel and volunteers (family and community counselling volunteers). Establish a warning system on risk factors at the community level, so that risk groups can be assisted in a timely manner.

v) **Increase the linkages between HIV responses and development programmes** as well as more effective and expanded coordination for AIDS planning at the national and provincial levels.
vi) **Improve mechanisms to prevent violations of the rights of people living with HIV and their families.** Procedures should be established to monitor such protection closely and regularly.

vii) **Emphasize the following in further research and development:**

a) Urging drug-producing countries, regional and international organizations and institutions, particularly pharmaceutical companies, to be actively involved in research and development of HIV vaccines and drugs, in order to help make HIV vaccines and HIV-related drugs more widely accessible and affordable by all those who need them in developing countries.

b) Development of national and international research infrastructure, laboratory capacity, improved surveillance systems, improved data collection, processing and dissemination.

### References and Bibliography


Wattana S. Janjaroen and Suwanee Khamman


Notes

1 This committee had four subcommittees on: Coordinating Information; Coordinating and Analysing Plans; Monitoring Implemented Plans; and Public Relations.

2 Personal communication from Thailand Network of People Living with HIV/AIDS, March 2005.

3 Much concern has been raised as to the inequity and appropriateness of the AIDS programmes financed by the Government, since AZT costs 45 Baht a day per PWA, while the government-financed school lunch programme costs 5 Baht per meal per student.

4 This unpublished study was conducted by the late Dr. Nicholas Prescott, Senior Economist at the World Bank, with the joint collaboration of MoPH, WHO and the World Bank.

5 There are five categories: (i) community economy; (ii) community welfare and safety; (iii) natural resource management and cultural presentation; (iv) community capacity building and networking; and (v) emergency community welfare.
Chapter 6

Limiting the Future Impact of HIV and AIDS on Children in Yunnan (China)

*China HIV/AIDS Socio-Economic Impact Study Team*

** Membership of the China Study Team included: Mark Hereward, George Ionita, Li Jianhua, Yuan Jianhua, Zhang Jiapeng, William Stewart and Li Xiaoliang

Currency: US$1.00 = approximately RMB 8

Yunnan: Socioeconomic profile

Yunnan, one of China’s poorer provinces, is in the south-central part of China. BORDERED by Myanmar to the west and the Lao PDR and Viet Nam to the south, it is on the edge of the ‘Golden Triangle’, of opium-growing fame. The province has 42 million inhabitants, one third of whom are ethnic minorities, mainly living in the mountainous border regions.

In 2000, Yunnan was the only province in China with a negative GDP growth rate (-2.4 per cent) when the national average was 7.1 per cent. In 1998, 2.7 million of Yunnan’s inhabitants (6.4 per cent) were found to be living below the poverty line, compared with a national average of 4.6 per cent of rural people and 1 per cent of registered urbanites (based on the Government’s poverty rate of <$0.66 per person per day; the World Bank’s standard is $1 per person per day). State Statistics Bureau rural household data for 1996 show Yunnan with 3.6 per cent of China’s 919.4 million rural people, but 15.3 per cent of the country’s 58 million rural poor. In 1999, Yunnan’s average per capita GDP was approximately $500 per annum (RMB 4,295), but average rural incomes were below $175. This discrepancy was mainly caused by the fact that one of the main cash crops is tobacco, which provides a good income to those engaged in processing and sales, but little for the farmer who grows the crop. However, cigarette tax revenues do allow the Yunnan Government to fund more basic social services than can be found in many of the other western provinces.

The province has 12 million children below the age of 15. The mortality rate for children below the age of five is reported to be less than 50 per 1,000, and the
MMR is around 100 per 100,000. In rural areas, 73 per cent of the people have access to safe drinking water, but only 34 per cent have access to sanitation. Primary school enrolment is quite high: 99.02 per cent of urban children, 97.42 per cent of rural children and 95.4 per cent of ethnic minority children are enrolled and the five-year retention rate is 80 per cent. However, although the Government now reports very high national enrolment rates for primary education (98.8 per cent in 1996), the United Nations Development Programme (UNDP) noted in 1998: ‘Actual school enrolment rates may be somewhat lower than officially reported rates.’ In some areas of China, enrolment rates are as low as 46 per cent, with girls accounting for three quarters of the children not enrolled in school (UNDP 1998).

In 2000, the incidence of malnutrition in children below the age of five in Yunnan was 15.9 per cent (15.1 per cent for boys and 16.8 per cent for girls), with malnutrition being much more prevalent in the countryside (20.4 per cent) than in the towns and cities (6.1 per cent).

Overview of HIV

China has three simultaneous HIV epidemics that are beginning to coincide. In the west and on the border with the Golden Triangle, intravenous drug use is the principal mode of transmission. Tainted blood and plasma transfusion is the predominant cause in the central provinces, while in coastal areas it is commercial sex.

In 2006, all indications point to these epidemics becoming explosively widespread in China, contributed to by already disquieting, but practically overlooked, increases in factors that facilitate the spread of the disease.

Nationally, the number of infections is rising rapidly (figure 1) and, between 2000 and 2001, the annual incidence to prevalence ratio rose from 30 per cent to more than 60 per cent. The Ministry of Health (MoH) reported 3,541 new infections in the first six months of 2001, a 67 per cent increase from the first half of 2000. In January 2006, MoH, UNAIDS and WHO estimated that there had been 70,000 new HIV infections in 2005 and a total of 650,000 people were living with HIV in the country, with an incidence of 0.05 per cent (www.unchina.org/unaids). China still ranks second in Asia after India, according to UNAIDS (UNAIDS 2004), but the organization has warned that HIV could begin to increase faster in Asia than it does in Africa.

Chinese HIV researchers explain the as yet relatively low incidence of HIV in China (0.1 per cent, 2003 (UNAIDS 2004)) with the fact that only recently have drug users and sex workers begun to mingle. Formerly, drug users clustered in ethnic minority areas in rural Yunnan province and Xinjiang region and were usually poor and less mobile. Sex workers were more mobile and generally resided in urban areas. This situation is changing rapidly (US Embassy 2000), coinciding with reductions in travel restrictions in the early 1990s.
HIV infection started in China in Yunnan’s Ruili County, with the first case being identified in 1986. During the 1980s, HIV infections were mostly associated with people with international contacts, but by the early 1990s, Yunnan had a more established epidemic, especially among intravenous drug users. Since 1995, that epidemic has spread along truck routes across and beyond Yunnan, in addition to the other epidemics related to heterosexual contacts and tainted blood.

In the 1990–1995 period, Yunnan accounted for 3 per cent of China’s population, but 50 per cent of the country’s HIV infections. But the HIV percentage has dropped dramatically as the epidemic has spread to other parts of China, so that it is projected that in 2010 only 3 per cent of China’s HIV cases will live in Yunnan.

General attitudes toward people with HIV and AIDS are very negative, despite the fact that the Ministry of Health has issued directives stating that people living with HIV are not to be discriminated against and on World AIDS Day 2003, Premier Wen Jiabao visited patients with HIV-related illness in hospital. Ethnographic and anecdotal evidence indicates people are shunned, dismissed from their jobs, evicted from their homes, and chased out of town when it becomes known that they are infected with HIV. People are generally unaware of the ways HIV can be contracted and levels of fear are very high. Many believe using the same chopsticks can pass on an infection. An ID card that identifies a person as being from an inland provincial village known to have a particularly high prevalence is sufficient to make him or her a pariah in surrounding areas. After unsubstantiated press reports that Henan farmers might be injecting watermelons with tainted blood, the villagers in Henan found it next to impossible to sell their produce, compounding their economic hardship.

**Figure 1. HIV reported cases and estimates for China and Yunnan Province**

Table 1. Estimated HIV prevalence for China

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Population</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>1,211 M</td>
<td>1,236 M</td>
<td>1,259 M</td>
<td>1,279 M</td>
<td>1,316 M</td>
<td>1,359 M</td>
</tr>
<tr>
<td>Yunnan</td>
<td>39.90 M</td>
<td>40.94 M</td>
<td>41.92 M</td>
<td>42.90 M</td>
<td>44.61 M</td>
<td>46.93 M</td>
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<td>Estimate total Adult HIV</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>10,000</td>
<td>100,000</td>
<td>500,000</td>
<td>&gt;1,000,000</td>
<td>5,000,000</td>
<td>20,000,000</td>
</tr>
<tr>
<td>Yunnan¹</td>
<td>5,100</td>
<td>27,000</td>
<td>40,000</td>
<td>54,000</td>
<td>200,000</td>
<td>600,000</td>
</tr>
<tr>
<td>Adult HIV prevalence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>&lt;0.002%</td>
<td>&lt;0.02%</td>
<td>&lt;0.1%</td>
<td>&lt;0.2%</td>
<td>&lt;1%</td>
<td>&lt;3%</td>
</tr>
<tr>
<td>Yunnan</td>
<td>0.0125%</td>
<td>0.054%</td>
<td>0.095%</td>
<td>0.17%</td>
<td>0.44%</td>
<td>1.32%</td>
</tr>
<tr>
<td>Male/female Ratio</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>9 to 1</td>
<td>7 to 1</td>
<td>5 to 1</td>
<td>4 to 1</td>
<td>3 to 1</td>
<td>2 to 1</td>
</tr>
<tr>
<td>Yunnan</td>
<td>10 to 1</td>
<td>6 to 1</td>
<td>6 to 1</td>
<td>5 to 1</td>
<td>4 to 1</td>
<td>3 to 1</td>
</tr>
<tr>
<td>Male HIV prevalence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>&lt;0.01%</td>
<td>&lt;0.05%</td>
<td>&lt;0.2%</td>
<td>&lt;0.5%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Yunnan</td>
<td>0.02%</td>
<td>0.09%</td>
<td>0.16%</td>
<td>0.27%</td>
<td>0.68%</td>
<td>1.91%</td>
</tr>
<tr>
<td>Female HIV prevalence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>&lt;0.001%</td>
<td>&lt;0.01%</td>
<td>&lt;0.02%</td>
<td>&lt;0.01%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Yunnan</td>
<td>0.002%</td>
<td>0.02%</td>
<td>0.03%</td>
<td>0.06%</td>
<td>0.18%</td>
<td>0.69%</td>
</tr>
</tbody>
</table>

Remarks: All figures exclude numbers for the epidemic in Henan Province, which went unreported, but is probably as serious as Yunnan’s. Past estimates are based on official estimates by the Ministry of Health (MoH) and the Chinese Academy of Preventive Medicine. Current and future estimates are based on the assumption that the epidemic doubling time is 30 months (annual increase of 30 per cent) and the total estimate in January 2001 was 1,250,000. The MoH Long Term Plan of 1998 describes a possible total of 10 million people infected with HIV by 2010, if no successful countermeasures are taken.

Surveillance systems

Surveillance and monitoring of HIV in China is carried out through the systematic collection of HIV rates at 101 national and a large number of provincial sites. Groups such as injecting drug users (IDUs), sex workers (SWs), patients with sexually transmitted infections (STIs), and long-haul lorry drivers are targeted. Data are also derived from antenatal screening in high prevalence areas. Surveillance site data are used to calculate and make estimates² on HIV distribution and prevalence. However, reported data do not contain results from sentinel surveillance, and prevalence does not include case-reported data, rendering scientifically valid data incomplete.
In addition, sentinel surveillance sites are located in cities, whereas more than two thirds of the HIV cases are in rural areas. Furthermore, surveillance systems were simply not designed for China’s unprecedented blood-related epidemic, and so miss localized areas of very high prevalence. Rapid assessments, better use of opportunistic infection data, or use of available data as an early warning system are needed.

Table 2. HIV among the general population in Yunnan from one surveillance site in a general hospital in the provincial capital, Kunming

<table>
<thead>
<tr>
<th>Year</th>
<th>Patients Tested</th>
<th>HIV-positive cases</th>
<th>Percentage HIV +</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td>2,388</td>
<td>4</td>
<td>0.2%</td>
</tr>
<tr>
<td>1993</td>
<td>1,776</td>
<td>9</td>
<td>0.5%</td>
</tr>
<tr>
<td>1994</td>
<td>2,048</td>
<td>4</td>
<td>0.2%</td>
</tr>
<tr>
<td>1995</td>
<td>795</td>
<td>6</td>
<td>0.8%</td>
</tr>
<tr>
<td>1996</td>
<td>800</td>
<td>5</td>
<td>0.6%</td>
</tr>
<tr>
<td>1997</td>
<td>807</td>
<td>3</td>
<td>0.4%</td>
</tr>
<tr>
<td>1998</td>
<td>800</td>
<td>1</td>
<td>0.1%</td>
</tr>
<tr>
<td>1999</td>
<td>800</td>
<td>11</td>
<td>1.4%</td>
</tr>
<tr>
<td>2000</td>
<td>805</td>
<td>11</td>
<td>1.4%</td>
</tr>
</tbody>
</table>

Yunnan has the best reporting system in China, which probably explains why it is the province with the majority of reported cases, but data at county level are still poor. Most case reports come from the sentinel surveillance system, which consists of: IDU surveillance sites, set up at compulsory detoxification centres, where the users are incarcerated; sex worker (SW) surveillance sites in female re-education centres; STI surveillance sites at selected STI clinics in various cities; and antenatal surveillance sites set up in the antenatal departments of general hospitals. Finally, there is a general population site, based in one hospital for unlinked serosurveillance, a feature that does not exist in the national system.

Table 3. Yunnan provincial sentinel surveillance sites

<table>
<thead>
<tr>
<th>Year</th>
<th>Provincial Sentinel Surveillance Sites</th>
<th>IDUs</th>
<th>SWs</th>
<th>STI Clinics</th>
<th>Antenatal</th>
<th>General</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td></td>
<td>11</td>
<td>2</td>
<td>9</td>
<td>2</td>
<td>1</td>
<td>25</td>
</tr>
<tr>
<td>1993</td>
<td></td>
<td>12</td>
<td>2</td>
<td>10</td>
<td>4</td>
<td>1</td>
<td>29</td>
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<tr>
<td>1994</td>
<td></td>
<td>13</td>
<td>2</td>
<td>10</td>
<td>5</td>
<td>1</td>
<td>31</td>
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<tr>
<td>1995</td>
<td></td>
<td>13</td>
<td>3</td>
<td>12</td>
<td>5</td>
<td>1</td>
<td>33</td>
</tr>
<tr>
<td>1996</td>
<td></td>
<td>14</td>
<td>3</td>
<td>17</td>
<td>6</td>
<td>1</td>
<td>40</td>
</tr>
<tr>
<td>1997</td>
<td></td>
<td>15</td>
<td>1</td>
<td>16</td>
<td>9</td>
<td>1</td>
<td>42</td>
</tr>
<tr>
<td>1998</td>
<td></td>
<td>14</td>
<td>1</td>
<td>15</td>
<td>11</td>
<td>1</td>
<td>42</td>
</tr>
<tr>
<td>1999</td>
<td></td>
<td>15</td>
<td>1</td>
<td>17</td>
<td>9</td>
<td>1</td>
<td>43</td>
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<tr>
<td>2000</td>
<td></td>
<td>15</td>
<td>1</td>
<td>15</td>
<td>10</td>
<td>1</td>
<td>42</td>
</tr>
</tbody>
</table>
All blood donors in Kunming and in the 15 prefecture capitals must be screened for HIV but these figures are excluded from provincial sentinel surveillance data.

### Modes of transmission

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Mode of transmission</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>2005 %</td>
<td>2010 %</td>
</tr>
<tr>
<td>IDU</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>60.0</td>
<td>75.6</td>
<td>77.0</td>
<td>65.4</td>
<td></td>
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</tr>
<tr>
<td>Yunnan</td>
<td>92.4</td>
<td>88.7</td>
<td>80.83</td>
<td>68.9</td>
<td>71</td>
<td>53</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td>China</td>
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<td>6.2</td>
<td>6.9</td>
<td>8.6</td>
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<td>Yunnan</td>
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<td>6.3</td>
<td>11.0</td>
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<td>23</td>
<td>38</td>
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<tr>
<td>China</td>
<td>0.4</td>
<td>0.4</td>
<td>0.3</td>
<td>-</td>
<td>-</td>
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</tr>
<tr>
<td>Yunnan</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>MTCT</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>China</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
<td>0.2</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Yunnan</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
<td>0.2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>32.2</td>
<td>18.1</td>
<td>15.6</td>
<td>25.5</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Yunnan</td>
<td>2.5</td>
<td>4.9</td>
<td>8.1</td>
<td>16.2</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

### Contaminated needles and blood

One of the most frequent modes of HIV transmission across China is contaminated injection needles, used either by drug abusers (accounting for 66.5 per cent of new cases) or by staff collecting blood or giving injections (as many as 200 million people estimated to be at risk from this route).

The five areas with the worst intravenous drug use problems are: Yunnan, Sichuan, and Guizhou provinces and the Xinjiang and Guangxi regions. The United Nations Drug Control Programme (UNDCP) estimates that around 60 per cent of the drugs originate in the Golden Triangle, and despite government efforts, Public Security sources report that less than 10 per cent of drugs are intercepted.
The Public Security Bureau detained 860,000 drug users in 2000, but estimates that the real number is 10 times that. From 1997 to 2000, the number arrested increased 65 per cent (from 520,000). According to national sentinel surveillance, over half the drug users are using drugs intravenously, and approximately one third sharing needles, partly to save money and partly because they see no danger in doing so. Researchers find a ‘blind confidence’ among drug users when it comes to HIV infections, with studies showing that male drug users are unwilling to use condoms, and female drug users (a small proportion of the total users) often engage in commercial sex activities.

In Yunnan between 50 per cent and 90 per cent of drug users inject intravenously. Moreover, the 1997 data analysis of the 15 drug-abuse surveillance points across the province showed an average incidence of needle sharing of 54.3 per cent.

Table 5. HIV and injecting drug users (IDUs) in Yunnan

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of surveillance sites</th>
<th>Number of IDUs tested</th>
<th>HIV-positive cases</th>
<th>% HIV-positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td>11</td>
<td>1,395</td>
<td>84</td>
<td>6%</td>
</tr>
<tr>
<td>1993</td>
<td>12</td>
<td>1,353</td>
<td>72</td>
<td>5%</td>
</tr>
<tr>
<td>1994</td>
<td>13</td>
<td>2,016</td>
<td>132</td>
<td>7%</td>
</tr>
<tr>
<td>1995</td>
<td>13</td>
<td>2,569</td>
<td>175</td>
<td>7%</td>
</tr>
<tr>
<td>1996</td>
<td>14</td>
<td>2,340</td>
<td>524</td>
<td>22%</td>
</tr>
<tr>
<td>1997</td>
<td>15</td>
<td>1,630</td>
<td>431</td>
<td>26%</td>
</tr>
<tr>
<td>1998</td>
<td>14</td>
<td>1,467</td>
<td>358</td>
<td>24%</td>
</tr>
<tr>
<td>1999</td>
<td>15</td>
<td>1,204</td>
<td>335</td>
<td>28%</td>
</tr>
<tr>
<td>2000</td>
<td>15</td>
<td>2,985</td>
<td>791</td>
<td>27%</td>
</tr>
</tbody>
</table>

An alarming number of people are contracting HIV either through transfusions of contaminated blood or via unsterilized equipment used when collecting blood. The illegal collection of blood and plasma products has been reported in China for a number of years. The fee of approximately $5 is a powerful incentive for poor farmers who have been known to give blood up to several times a month. The frequency is facilitated by the fact that, after pooling the blood of the same type and separating out the plasma to make gamma globulin and albumin, the remaining components can be re-injected into the farmers. An October 1998 law banning blood donations for pay has helped reduce the scale of this activity but chronic blood shortages and the financial incentives have made it difficult to eliminate entirely. Some Chinese researchers estimate that in Henan province (population of 100 million) alone, there are approximately 1 million people infected with HIV from blood donations. Although in Yunnan the contraction of HIV via blood plasma sales does not appear to represent a major problem, there are a number of other
provinces such as Hubei (pop. of 60 million), Hebei (pop. of almost 70 million) and Shanxi (pop. over 30 million) with villages where up to 62 per cent of the donors are HIV-positive.

**Sexual transmission**

The spread of HIV through sexual intercourse is gaining momentum, mostly in the eastern provinces. This includes both heterosexual (particularly via 4–5 million female SWs who have as clients an estimated 1 per cent of all men in China) and homosexual (an estimated 8 million men practise male-to-male sex).

STIs are increasing at an alarming rate (see figure 6), especially in the wealthier parts of China, such as the cities of Shanghai and Beijing, and Zhejiang, Jiangsu, Guangdong and Hainan provinces, where the number of cases quadrupled from 1994 to 2000 (US Embassy 2000). The national reported prevalence for 2000 was 1 million, estimated to be only one tenth of the actual figure.

The infection is also beginning to move beyond drug users in Yunnan. The proportion of HIV carriers who were drug users fell from 87 per cent in 1997 to an estimated 70 per cent in 2002, with 14 per cent of HIV infections being ascribed to sexual activity. In Yunnan, sexual transmission started to increase in mid-1997 and reached 15 per cent in 2000. In 2000, HIV prevalence among male STI patients averaged 2.7 per cent, and increased rapidly in Binchuan, Gengma, Chuxiong and Kunming. Sex workers in Kunming have HIV prevalence of 2.9 per cent, while female STI patients averaged 1.9 per cent. Many women, particularly those in rural areas, also suffer from reproductive tract infections (RTI); according to numerous studies, as many as two thirds have some type of RTI. These can serve as a reliable proxy for STIs, which in turn serve as a reliable proxy for HIV (UNAIDS and WHO 2000).

**Homosexual transmission**

Because of social norms, most homosexuals are married. Studies indicate that 2.2 per cent of rural married men and 0.5 per cent of urban married men have had homosexual sex. Other studies have found up to 5 per cent of men having sex with men (MSM) to be HIV-positive (Li 2001).

A survey among 857 MSM (average age 30 years) from throughout China in 2000 indicated that 59 per cent had also had sex with a woman in the past year, and of the 71 who had taken an HIV test, 3 were positive (Zhang Beichuan 2001).

**Mother-to-child transmission (MTCT)**

Since 1992, when antenatal screening for HIV was first introduced, the percentage of mothers testing HIV-positive has remained relatively constant at approximately
0.2 per cent. Whether or not the HIV-positive mothers have definitely passed on the virus to their children is not known, but in 2002 there were estimates in Yunnan of 500 children having been infected by their mothers. With an increasing number of women becoming HIV-positive, this number will inevitably rise. Assuming an average three-year survival time for an HIV-positive child, it is estimated that by 2005 almost 6,000 children will be infected, and by 2010 the total figure will have jumped to 16,000 (see figure 2). These children will not only be ill themselves, up to a third probably dying in their first year of life, they are also likely to be orphaned very early in life.

Table 6. Screening for HIV in antenatal clinics

<table>
<thead>
<tr>
<th>Year</th>
<th>Surveillance sites</th>
<th>Antenatal consultations tested for HIV</th>
<th>HIV-positive cases</th>
<th>% HIV-positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td>2</td>
<td>1,240</td>
<td>2</td>
<td>0.2%</td>
</tr>
<tr>
<td>1993</td>
<td>4</td>
<td>1,346</td>
<td>2</td>
<td>0.1%</td>
</tr>
<tr>
<td>1994</td>
<td>5</td>
<td>2,875</td>
<td>4</td>
<td>0.1%</td>
</tr>
<tr>
<td>1995</td>
<td>5</td>
<td>2,896</td>
<td>2</td>
<td>0.1%</td>
</tr>
<tr>
<td>1996</td>
<td>6</td>
<td>3,275</td>
<td>8</td>
<td>0.2%</td>
</tr>
<tr>
<td>1997</td>
<td>9</td>
<td>5,751</td>
<td>8</td>
<td>0.1%</td>
</tr>
<tr>
<td>1998</td>
<td>11</td>
<td>6,521</td>
<td>12</td>
<td>0.2%</td>
</tr>
<tr>
<td>1999</td>
<td>9</td>
<td>6,417</td>
<td>14</td>
<td>0.2%</td>
</tr>
<tr>
<td>2000</td>
<td>10</td>
<td>8,698</td>
<td>21</td>
<td>0.2%</td>
</tr>
</tbody>
</table>

Figure 2. Projection of children in Yunnan with HIV infection from MTCT
Patterns of infection

Rural/urban

The pattern of infection in Yunnan is also changing from the predominantly rural, ethnic minority people living in border areas, to a more urban setting often far from the borders (figure 3). Of the HIV cases reported in 1990, 93.8 per cent were among peasants and farmers, but in 2000 only 32.9 per cent were among the rural population. The percentage of infected people who were officially unemployed, however, increased from 7.6 per cent in 1990 to 44.1 per cent in 2000. In the same period, the percentage of infected salaried employees rose from zero to 4.7 per cent, sounding a warning that HIV was spreading from the countryside to the cities. The remaining 18.3 per cent were self-employed workers, truck drivers, taxi drivers, etc.

Figure 3. Urban–rural distribution of HIV in Yunnan

The case of Kaiyuan City illustrates how HIV spreads via drug use from rural to urban areas. Kaiyuan is located in the south-east of the province, and has a population of 292,094, consisting of 33 different minority groups. Situated 300 kilometres from the Vietnamese border, on the main Kunming–Hanoi railway, and at the centre of a well-developed road network, it is a focal point for trade with bordering countries. With more than 7,000 long-distance truck drivers living in the city and over 30,000 people passing through it daily, Kaiyuan has become an entertainment centre. There are 34 beauty and massage salons, 61 discos, 124 karaoke bars and 5 saunas, employing over 2,000 female workers. By the end of 2000, 332 people, most of them intravenous drug users, had tested positive for HIV.

Age group

As shown in figure 4, HIV-positive people are predominantly in their twenties.

Gender patterns

It is mainly males who are HIV-positive in Yunnan, but the ratio of male to female infections dropped significantly in the last decade of the 20th century. In 1990 it was 40:1 and by 2000 there were only six males infected for every one female. Nationally, the ratio is 4:1, but falling.
Ethnic patterns
The ethnic distribution of the infection changed greatly during the 1990s.

Figure 5. Changing pattern of HIV distribution among ethnic groups in Yunnan

Facilitating factors
Drug abuse
The main characteristics of drug use in Yunnan are:
1. **Number**: 100,000 to 150,000 (2002 estimate).
2. **Age**: Drug users are mainly young people. Most begin by smoking drugs and then convert to injection after six months to a year.
3. **Sex:** Males outnumber females, but there is a steady increase in the number of females becoming addicted.

4. **Occupation:** Young peasants are the main group in rural areas, while in towns and cities it is predominantly people with unstable jobs.

5. **Location,** rather than ethnic origin, is the major factor.

6. **Levels of education:** Drug users in general have low levels of education.

7. **Drugs used:** Heroin has gradually overtaken smoked opiates as the major drug, especially in urban areas. In poor and remote mountain areas, however, opium smoking is the main addiction among older people. The use of stimulants has been gaining popularity among adolescents, usually in poor rural areas, the most commonly used stimulants being ecstasy and ‘ice’ (methamphetamine).

8. **Social impact:** Estimates show drug users are responsible for 70–80 per cent of robberies, thefts and drug dealing.

9. **Relapse rate:** More than 90 per cent of drug users relapse after going through detoxification.

   A survey of 843 intravenous drug users in two counties and one city of Yunnan showed that they engaged in high-risk sexual behaviour, with several partners and a very low condom use rate (2.5 per cent). There were similar findings from a survey of 364 heroin users in Kunming: 41 per cent had more than five sex partners and 85.2 per cent never, or only occasionally, used condoms.

**Sexually transmitted infections**

As seen in figure 6, a cumulative total of 49,955 STI cases were reported from 1985 to 2000 from 26 STI surveillance sites in Yunnan. In 2000, there were 12,290 reported STI cases, an increase of 61.05 per cent over 1999, although this figure is believed to be well below the real prevalence level. In a 1999 survey conducted by the Yunnan STD Prevention Monitoring Centre in 135 state-owned hospitals and health institutions, and 167 clinics in eight prefectures in Yunnan province, the percentage of unreported cases was 19.1 per cent in state-owned institutions, 62.4 per cent in health centres, 79.3 per cent in medical institutions, and 100 per cent in private-owned hospital and clinics. A survey of 222 people with STI symptoms visiting a doctor for the first time shows that 41 per cent visited public health STI clinics, 42 per cent visited private hospitals and clinics, and 17 per cent clients went to pharmacies for self-treatment (Zeng Yong 1997).
## Table 7. Profiles of registered drug abusers in Yunnan by year

<table>
<thead>
<tr>
<th></th>
<th>1998) Number (%)</th>
<th>1999 Number (%)</th>
<th>2000 Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of drug users</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>40,253 (90%)</td>
<td>39,482 (89%)</td>
<td>39,293 (89%)</td>
</tr>
<tr>
<td>Female</td>
<td>4,656 (10%)</td>
<td>5,074 (11%)</td>
<td>4,949 (11%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44,909</strong></td>
<td><strong>44,556</strong></td>
<td><strong>44,245</strong></td>
</tr>
<tr>
<td><strong>Type of drug abuse</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heroin</td>
<td>18,630 (64%)</td>
<td>19,763 (67%)</td>
<td>19,910 (69%)</td>
</tr>
<tr>
<td>Opium</td>
<td>10,581 (36%)</td>
<td>9,855 (33%)</td>
<td>9,026 (31%)</td>
</tr>
<tr>
<td>‘Ice’</td>
<td>0 (0%)</td>
<td>44 (0.1%)</td>
<td>37 (0.1%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>29,211</strong></td>
<td><strong>29,662</strong></td>
<td><strong>28,973</strong></td>
</tr>
<tr>
<td><strong>Injecting heroin users</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of People</td>
<td>15,662</td>
<td>14,872</td>
<td>15,247</td>
</tr>
<tr>
<td>Percentage among heroin users</td>
<td>84</td>
<td>75</td>
<td>77</td>
</tr>
<tr>
<td><strong>Age distribution</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below age 17</td>
<td>813 (2%)</td>
<td>956 (2%)</td>
<td>961 (2%)</td>
</tr>
<tr>
<td>Between ages 18–25</td>
<td>14,207 (32%)</td>
<td>14,755 (33%)</td>
<td>14,707 (33%)</td>
</tr>
<tr>
<td>Between ages 26–35</td>
<td>16,669 (37%)</td>
<td>16,254 (36%)</td>
<td>16,789 (38%)</td>
</tr>
<tr>
<td>Between ages 36–60</td>
<td>10,435 (23%)</td>
<td>10,032 (23%)</td>
<td>9,572 (22%)</td>
</tr>
<tr>
<td>Over age 60</td>
<td>2,765 (6%)</td>
<td>2,559 (6%)</td>
<td>2,216 (5%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44,889</strong></td>
<td><strong>44,556</strong></td>
<td><strong>44,245</strong></td>
</tr>
<tr>
<td><strong>Occupation distribution</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Workers</td>
<td>3,409 (8%)</td>
<td>3,280 (7%)</td>
<td>3,113 (7%)</td>
</tr>
<tr>
<td>Peasants</td>
<td>27,255 (61%)</td>
<td>27,079 (61%)</td>
<td>27,325 (62%)</td>
</tr>
<tr>
<td>Cadres*</td>
<td>214 (0.5%)</td>
<td>212 (0.5%)</td>
<td>209 (0.5%)</td>
</tr>
<tr>
<td>Self-employed workers</td>
<td>1,378 (3%)</td>
<td>1,446 (3%)</td>
<td>1,238 (3%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>12,143 (27%)</td>
<td>12,163 (28%)</td>
<td>11,973 (27%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44,399</strong></td>
<td><strong>44,180</strong></td>
<td><strong>43,858</strong></td>
</tr>
<tr>
<td><strong>Levels of education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterates</td>
<td>10,270 (23%)</td>
<td>9,532 (21%)</td>
<td>8,576 (19%)</td>
</tr>
<tr>
<td>Primary school</td>
<td>14,826 (33%)</td>
<td>15,161 (34%)</td>
<td>15,781 (36%)</td>
</tr>
<tr>
<td>Junior high</td>
<td>16,958 (38%)</td>
<td>16,980 (38%)</td>
<td>17,017 (38%)</td>
</tr>
<tr>
<td>Senior high</td>
<td>2,768 (6%)</td>
<td>2,762 (6%)</td>
<td>2,765 (6%)</td>
</tr>
<tr>
<td>College</td>
<td>87 (0.2%)</td>
<td>121 (0.3%)</td>
<td>109 (0.2%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44,909</strong></td>
<td><strong>44,556</strong></td>
<td><strong>44,248</strong></td>
</tr>
<tr>
<td><strong>Consequences</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Disease</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV</td>
<td>1,706</td>
<td>1,415</td>
<td>1,507</td>
</tr>
<tr>
<td>STIs</td>
<td>519</td>
<td>609</td>
<td>482</td>
</tr>
<tr>
<td>Other related diseases</td>
<td>962</td>
<td>858</td>
<td>839</td>
</tr>
<tr>
<td>Handicapped</td>
<td>64</td>
<td>54</td>
<td>51</td>
</tr>
<tr>
<td><strong>Deaths</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deaths caused by drug use</td>
<td>157</td>
<td>117</td>
<td>182</td>
</tr>
<tr>
<td>Other deaths</td>
<td>59</td>
<td>60</td>
<td>115</td>
</tr>
<tr>
<td><strong>Drug-related crimes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2,420</td>
<td>2,399</td>
<td>2,252</td>
</tr>
</tbody>
</table>

* Cadres: civil servant leaders of factories, institutions, communities, police and military.
Figure 6. Sexually transmitted infections in China and Yunnan Province

![STDs in China and Yunnan (reported and estimates)]

Table 8. HIV among patients consulting on STIs in Yunnan

<table>
<thead>
<tr>
<th>Year</th>
<th>Surveillance sites</th>
<th>Number of STI cases tested for HIV</th>
<th>HIV-positive cases</th>
<th>% HIV-positive STI patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td>9</td>
<td>2,040</td>
<td>1</td>
<td>0.0</td>
</tr>
<tr>
<td>1993</td>
<td>10</td>
<td>2,112</td>
<td>2</td>
<td>0.1</td>
</tr>
<tr>
<td>1994</td>
<td>10</td>
<td>2,170</td>
<td>4</td>
<td>0.2</td>
</tr>
<tr>
<td>1995</td>
<td>12</td>
<td>3,595</td>
<td>5</td>
<td>0.1</td>
</tr>
<tr>
<td>1996</td>
<td>17</td>
<td>4,316</td>
<td>53</td>
<td>1.2</td>
</tr>
<tr>
<td>1997</td>
<td>16</td>
<td>3,927</td>
<td>126</td>
<td>3.2</td>
</tr>
<tr>
<td>1998</td>
<td>15</td>
<td>3,658</td>
<td>57</td>
<td>1.6</td>
</tr>
<tr>
<td>1999</td>
<td>17</td>
<td>4,430</td>
<td>84</td>
<td>1.9</td>
</tr>
<tr>
<td>2000</td>
<td>15</td>
<td>4,245</td>
<td>103</td>
<td>2.4</td>
</tr>
</tbody>
</table>

Table 9. Survey on the behaviour of young people in Yunnan

<table>
<thead>
<tr>
<th></th>
<th>Have a boy/girlfriend</th>
<th>Have sex with their boy/girlfriend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Menglian county</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boys (207)</td>
<td>51%</td>
<td>43%</td>
</tr>
<tr>
<td>Girls (191)</td>
<td>59%</td>
<td>40%</td>
</tr>
<tr>
<td>Kunming</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boys (101)</td>
<td>29%</td>
<td>38%</td>
</tr>
<tr>
<td>Girls (64)</td>
<td>28%</td>
<td>56%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Have an extramarital sexual partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married men (149)</td>
</tr>
<tr>
<td>Married women (149)</td>
</tr>
</tbody>
</table>
The reasons for the rise in STIs are complex and various, but they include increased mobility, social change and the deterioration of the health system. Commercial sex is rising, and experts estimate that about 0.5–1 per cent of all adult males visit sex workers. As shown in table 9, Yunnan young people’s attitudes towards sex are relatively relaxed, with from over a third to half engaging in premarital sex.

A survey of 222 STI patients in Yunnan revealed their socioeconomic status.

Table 10. Profile of 222 patients attending STI clinics in Kunming, 1997

<table>
<thead>
<tr>
<th>Age distribution</th>
<th>Between 15–19 years</th>
<th>5%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Between 20–29 years</td>
<td>46%</td>
</tr>
<tr>
<td></td>
<td>Between 30–39 years</td>
<td>32%</td>
</tr>
<tr>
<td></td>
<td>Between 40–49 years</td>
<td>11%</td>
</tr>
<tr>
<td></td>
<td>Over age 50</td>
<td>5%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Occupation distribution</th>
<th>Workers</th>
<th>14%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Peasants</td>
<td>28%</td>
</tr>
<tr>
<td></td>
<td>Cadres</td>
<td>14%</td>
</tr>
<tr>
<td></td>
<td>Self-employed workers</td>
<td>13%</td>
</tr>
<tr>
<td></td>
<td>Drivers</td>
<td>4%</td>
</tr>
<tr>
<td></td>
<td>Promoters</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td>Students</td>
<td>1%</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>10%</td>
</tr>
<tr>
<td></td>
<td>Jobless</td>
<td>14%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Levels of education</th>
<th>Illiterate</th>
<th>3%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Primary school</td>
<td>18%</td>
</tr>
<tr>
<td></td>
<td>Middle school</td>
<td>70%</td>
</tr>
<tr>
<td></td>
<td>College</td>
<td>9%</td>
</tr>
</tbody>
</table>

Source: Zeng Yong, ‘Health Seeking and Reproductive Health Behaviour of Persons with STDs’.

Commercial sex

China’s rapidly expanding commercial sex trade increases the risk of HIV infection for urban populations. From 1996 to 2000, the number of sex workers arrested increased by 43 per cent to 600,000. However, the Public Security Bureau (PSB) estimates the total number of sex workers to be five or 10 times higher, with some Chinese researchers estimating as many as 20 million.

Most experts say that some sex workers are IV drug users, and that the two populations have begun to intermingle, spreading HIV outside the circle of drug users.
In the 2000 HIV monitoring report by Yunnan province, the seroprevalence of HIV among women sex workers was 2.9 per cent, but among female drug users arrested for commercial sex activities it was as high as 10.3 per cent. Sex work and drug use are both considered to be crimes, and offenders are sent to rehabilitation camps and centres. Ironically, these centres offer a further risk as inmates commonly tattoo themselves with non-sterilized needles.

SWs are especially at risk, since most have little access to health information, health services or counselling. Although HIV infection rates among SWs are still thought to be low, the Government reports that an average of 30 per cent of the SWs in women’s custody and education centres were infected with STIs. Testing for STIs and HIV is not available free of charge. A study conducted by the National STD Control Centre in Nanjing for the European Union indicated an average cost of 400–500 Yuan, and treatment often costs thousands of Yuan. In some women’s custody and re-education centres in the south, treatment for STIs is only provided to those inmates who are able to pay (Human Rights in China 1998).

Wang Yanguang of the Chinese Social Sciences Academy’s Philosophy Institute, in an April 2000 article titled ‘Strategy of Tolerance and HIV/AIDS Prevention in China’, stated: ‘The rapid growth of China’s sex industry is not simply a matter of the moral fall of those women who sell themselves. The context of this problem includes rapid economic development, a growing gap between rich and poor, in both cities and countryside, unemployment, poverty, and a big buyer’s market. Under these conditions, there are no simple solutions that could make the sex trade disappear in a short time.’

Table 11. HIV among SWs in Yunnan

<table>
<thead>
<tr>
<th>Year</th>
<th>Nr surveillance sites</th>
<th>Total SWs tested</th>
<th>HIV-positive SWs</th>
<th>% HIV-positive SWs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td>2</td>
<td>426</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>1993</td>
<td>2</td>
<td>126</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>1994</td>
<td>2</td>
<td>83</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>1995</td>
<td>3</td>
<td>1,050</td>
<td>5</td>
<td>0.5%</td>
</tr>
<tr>
<td>1996</td>
<td>3</td>
<td>824</td>
<td>12</td>
<td>1.5%</td>
</tr>
<tr>
<td>1997</td>
<td>1</td>
<td>588</td>
<td>9</td>
<td>1.5%</td>
</tr>
<tr>
<td>1998</td>
<td>1</td>
<td>575</td>
<td>14</td>
<td>2.4%</td>
</tr>
<tr>
<td>1999</td>
<td>1</td>
<td>847</td>
<td>19</td>
<td>2.2%</td>
</tr>
<tr>
<td>2000</td>
<td>1</td>
<td>820</td>
<td>24</td>
<td>2.9%</td>
</tr>
</tbody>
</table>
So, whereas in Yunnan clients are from lower classes (inferred from STI clinic attendees table 10), in the east, clients come from higher social classes.

**Low condom use**

Although the Government purchases 1.2 billion condoms a year from domestic sources for free distribution, primarily as contraceptives, the use of condoms remains very low throughout China. In Yunnan, research conducted mainly by the Australian Red Cross found that, while levels of knowledge about condoms was generally good in cities (95 per cent of the 524 young people surveyed in Kunming could tell where to buy condoms), usage rates were low, and in rural areas over 40 per cent of the 397 young people surveyed (in Menglian county) did not know what a condom was and another 40 per cent had no idea where to buy them.

Some research shows ethnic minority groups seem to regard the use of condoms as ‘taboo’. For example, the Dai people would not want to use condoms and the Dai women said they never used them, as did most of the Naxi women. Usage levels are generally low, but are related to socioeconomic factors.

Many SWs find it difficult to persuade clients to use condoms. In a survey conducted by Xu Yansheng and her group in a re-education camp for women in Kunming, although 91.4 per cent of the women knew that condoms were used to prevent disease, 61.1 per cent had clients who refused to wear them and only 33.3 per cent used the protection every time they had sex with clients. In a 1997 survey conducted by Wu Zunyou and his group among 40 service girls in 52 bars and hair
salons in Luxi, Ruili and Longchuan, Dehong prefecture, only 10 per cent, all in Ruili, said they used condoms every time. In 2001, Li Jianhua and his group interviewed 40 ‘street’ sex workers with an average age of 27.54±5.32 in Kunming city, Menglian county, Jinhong county and Ruili city. The number of visitors they received varied from day to day with a maximum of three clients and a minimum of one visitor per night, each paying RMB 20–50. All 40 interviewees had condoms with them all the time and most of them would ask their clients to use them, but 92.5 per cent would not insist if the visitors refused. They said, however, they would refuse sex if the client had an STI, which they thought they could determine visually. None of them used condoms with their long-term partners.

Police practices in some parts of the country actually discourage the use of condoms. As an official told researchers:

The main reason prostitutes give for why it is ‘inconvenient to carry’ condoms is that police consider carrying condoms as legal evidence of prostitution. This demonstrates that our policy of attacking prostitution has a threatening effect, since most prostitutes feel more threatened by the law than by STIs. It is very difficult to determine if someone is involved in prostitution. When you detain a woman and take her in for investigation, the most important evidence is whether or not she is carrying condoms. If you don’t discover any condoms, you can only prove she is a prostitute if she admits to soliciting customers.

In 1998 and 2000, surveys were conducted on the state of condom use by drug abusers. In Yang Fang’s 1998 survey of 364 drug abusers, 94.5 per cent knew something about condoms, but 48.26 per cent (36.33 per cent men and 60.08 per cent women) said they did not know how to use them, and only about half knew that condoms could reduce the risk of STIs (55.2 per cent) and HIV (44.8 per cent). In Wu Zunyou’s 2000 survey, high-risk behaviours were very common, particularly among the female drug abusers: 50 per cent engaged in sex work and 66.2 per cent never used condoms with their clients or partners.

Unsafe injections

WHO estimates that 50 per cent of the curative injections in China are unsafe. Certain studies have found 88 per cent to be unsafe because of improper sterilization of equipment (17 per cent) and unsafe injection practices (40 per cent), or both (43 per cent). In one study, fewer than half the medical workers knew how to sterilize properly and 56 per cent said they only changed needles when they noticed blood on the syringe (Journal of Epidemiology 1999).

On average, rural Chinese receive seven prescriptions per year, 70 per cent of which involve injections. If 50 per cent of these were unsafe, there would be 3,347
new HIV infections per annum in Yunnan’s rural population, three times the number of infections from MTCT. WHO modelling from 2001 suggests that 2 per cent of HIV infections can be traced to injections.

The potential risk for children is equally high: If one considers that 50–88 per cent of rural injections are unsafe, with Yunnan’s general seroprevalence of 0.2 per cent, and the risk of HIV transmission through each injection being 3 per cent, for the average child below the age of five receiving six injections a year, the risk of contracting HIV each year would be 0.03 per cent. Over a six-year period, the child therefore has a 2-in-1,000 chance of becoming infected with HIV, twice the chance that a man has of contraction through unprotected sex (1 per 1,000 sexual encounters with HIV-positive women, according to WHO WPRO). Yunnan has an under-five child population close to 4 million. Given the above, this would lead to 1,267 new infections each year in children below the age of five, 15 per cent more than the estimate of HIV infections derived from MTCT (1,103) in the year 2000.

Health care system

Mortality rates have increased in some areas since the early 1990s, particularly in the less-developed western part of the country. The fundamental cause is that there has recently been a substantial erosion in the quality and efficiency of health care (UN Country Team 2000). The past two decades have seen a shift from a low-cost socialized health care system to a market-oriented one, with charges that are prohibitively high for many citizens. This change has come about without a corresponding updating of policies or laws to regulate payments and operations. Few have insurance, so the rapid escalation of costs has meant reduced personal spending on other service sectors such as education (UN Country Team 2000), and in 40 per cent of rural households, the cause of their descent below the poverty line was said to be recent medical expenditure.

From 1990 to 1997, outpatient and inpatient costs increased 400–500 per cent. Medications accounted for the bulk of expenditure (70–80 per cent of all expenses in 1994), due mainly to their overuse. In order to make a living, rural health practitioners often over-prescribe treatment. Medical cost increases far exceed income and GDP growth (average of 8–10 per cent per year). The rapid rise in user costs correlates directly with decreased utilization. A 1992–1993 survey found that, of those who had been referred to a hospital for care, 40.6 per cent did not go, on grounds of excessive costs and inability to pay. The average hospital cost is RMB 1,273 at the county level and RMB 6,244 nationally; average annual income in 1997 was RMB 6,079. This is particularly disturbing in a country where insurance coverage is so rare.
Preventative and primary services such as immunizations and prenatal care have also declined. Maternity and childcare clinics tend to lack funds for personnel expenses or operating costs, and therefore cut services that do not produce income. Only 29 per cent of mothers in poor counties can afford prenatal exams, and only 6 per cent can afford a hospital delivery, with only 36 per cent of deliveries meeting basic hygiene standards. This problem is known to contribute to higher IMR and MMR. In fact, fieldwork data suggest that the high costs and lack of specialists, female doctors and postnatal care place women at particular risk. Their health is already compromised by overwork and malnutrition and female workers and health officials in Yunnan have emphasized that women are the most likely to become seriously ill (Human Rights in China 1998).

Access is often a matter of geography as well as cost: there are city hospitals, hospitals for ethnic minorities and farm hospitals at the municipal level, as well as private clinics in villages and townships, but villages are often over 10 kilometres away from the nearest health centre.

For people seeking to treat themselves in pharmacies, there is the added risk of counterfeit medicines. According to Chinese health authorities, 194,000 died of reactions to bad medicines in 1998, far higher than the number who died that year of communicable diseases. A drug market sampling by the State Drug Administration on February 6, 1999 reported that the proportion of impure drugs is highest in Chinese traditional medicine. Of 387,000 drug products sampled, 13 per cent failed to meet standards (Cai Jianwen 2000).

The situation is particularly acute for people suffering from HIV-related illnesses. First of all, there are few HIV-related health services available in China. Those that do exist come under the system for treating infectious diseases – a system that is known to be weak, particularly in dealing with STIs. There are fewer than 200 doctors who have specialized skills in diagnosing or treating HIV-related illnesses (UNAIDS 2004) and there is little or no provision for counselling those who test positive. Furthermore, discrimination against PLHIV by health workers is widespread, most seriously in urban areas. Thus, some general hospitals, and even AIDS hospitals in Beijing, refuse to perform surgery on patients with HIV-related illness. A study of HIV-positive families in Ruili, Yunnan (Zhang Jiapeng 1999), found that medical workers at the township and village levels were more sympathetic to patients with HIV-related illness than those in cities and provided necessary medical services even if they knew the patient’s HIV status.

Tuberculosis epidemic

MoH experts say that the tuberculosis (TB) situation in China has become critical (Beijing Youth Daily 2001). China ranks second in the world (after India) in the
total number of people with TB. A third of the population, more than 400 million, have been exposed to the TB bacillus, 6 million have active TB, and 2 million are contagious carriers. Over 150,000 die from TB each year, twice the number of deaths in China from all other contagious diseases combined. The rate of TB in the Chinese countryside is 2.4 times that in urban areas.

The official figures may, in fact, be low, because a survey found that about half of the people who were TB-positive had not been registered, while 65.9 per cent of the people with symptoms were not diagnosed. Three quarters of the active TB cases are aged 15–34, meaning that China loses 360 million working days each year to the disease.

The overlapping of the HIV and TB epidemics poses a significant threat because of the following:

- TB is the leading cause of death among people living with HIV (PLHIV); a third of PLHIV die of TB.
- TB accelerates the course of HIV infection and enhances HIV replication in vivo; long-term survival is reduced by half compared to PLHIV who never develop TB.
- Populations vulnerable to HIV are traditionally the same as those vulnerable to TB (WHO China 2001).

**Low awareness of HIV and STIs**

A Chinese proverb says that one can do anything in China, as long as one does not talk about it. Although the average age of first sexual encounter is dropping and the frequency of premarital and extramarital relations rising, there is little open discussion about the trend.

A UNICEF-sponsored State Family Planning Survey of 7,000 people in six provinces (December 2000) indicated that nearly 20 per cent of respondents had never heard of HIV and AIDS; 71 per cent said they knew HIV was highly infectious, but most of them had no clear idea of how the virus could spread; 62 per cent said they knew they could take precautions to prevent being infected but did not know how to do so.

Another UNICEF survey of 10,000 young people in 17 Pacific-East Asia countries (2001) revealed that Chinese adolescents (9–17 years) were ‘woefully unprepared’ to handle HIV, since 48 per cent said they knew “absolutely nothing” about HIV and AIDS or “only knew the name”.
There is likely to be even less awareness of the dangers of HIV among minority groups, as their members tend to be poor with lower levels of education and literacy. Moreover, their poverty restricts their ability to adopt safer practices.

**Unprecedented migration**

Many of China’s HIV-infected people come from the 100 million migrants, up to one third of the workforce, who move around the country looking for work opportunities. It is relatively difficult to study this group, but in an October 2000 article, the Shanxi Province Epidemiology Station reported that, out of 176 HIV cases, two thirds were migrant workers, nearly half of whom were from outside the province (US Embassy 2000).

In Yunnan, approximately 1 million migrate to the provincial capital and many others leave Yunnan for Guangdong, the prosperous province to the east. Many migrants, especially those travelling short distances, are men on their own, and are presumed to visit SWs. Long-distance lorry drivers are also considered at risk, since many rest stops and restaurants are associated with commercial sex.

**National and provincial government responses to HIV and AIDS**

**National government response**

Since 1994, when the Government signed the Paris Declaration at the International AIDS Summit, some progress has been made in updating national policies, laws and regulations in a number of areas pertaining to HIV and AIDS. However, an effective response in China is still hampered by such factors as insufficient political commitment or resources at many levels and a lack of effective policies and determination to carry them out.

Despite the image of a centralized command economy, budgets in China are dependent on the local ability to raise funds. Therefore, although there is a central budget for HIV, it only applies to central level activities – provincial and county initiatives have to be funded locally. In 1995, the central funding level was RMB 5 million ($600,000). From 1996 to 2001 this was increased to the equivalent of $1.8 million. Then in 2001, the Government set the annual budget at $12 million for HIV prevention and control, and over $117 million to improve blood safety (UN Country Team 2001).

Awareness of the full implications of HIV is still insufficient, even among decisionmakers, and the response remains overly medical, a constraint that is
exacerbated by the state of the health system. There is an urgent need, for instance, to improve the situation with regard to the diagnosis and treatment of STIs. But in order to curb the potentially widespread epidemic, all relevant sectors at all levels need to be involved, together with the people currently living with HIV, so that there can be improved levels of knowledge about HIV and care for those with HIV-related illnesses. Raising HIV awareness and increasing behavioural change will entail capacity building, training and information dissemination to promote life skills and healthy habits among vulnerable young people. Policies and strategies are also needed to facilitate community care and protection of the rights of PLHIV (UN Country Team 2001).

**Provincial government response**

Yunnan province has responded to the challenge of the HIV epidemic by implementing a series of central government laws and regulations on the control and prevention of HIV and STIs, and by carrying out its provincial level policies.

Yunnan has been very active in courting outside support for all development activities, including in the area of HIV and AIDS. A listing of international partners (DFID, UNICEF, UNAIDS, SCF-UK, Red Cross-Australia, Oxfam-HK, Salvation Army-HK, MSF Holland, Ford Foundation) illustrates the international nature of the partnerships for activities that include surveillance, planning, monitoring, education/communication and advocacy. Of all provinces in China, Yunnan has the widest variety of interventions, including training multiple sectors to respond to HIV, screening of blood, reproductive health care, school health education and working with drug users and sex workers. So far, the HIV prevalence is relatively low, but any predictive model will need to identify possible bridges between high-risk and general populations. Otherwise, the likelihood of a swift transition to infection of the general population is high.

Yunnan began budgeting funds for prevention and surveillance of HIV from 1990 onwards and then halfway through the decade increased the budget to RMB 2 million for prevention and RMB 3 million for infrastructure and equipment. By the end of the decade, the annual prevention budget had doubled, bringing the total to RMB 22 million for prevention and RMB 18 million for infrastructure. Between 1996 and 2000, international organizations contributed over RMB 33 million to Yunnan’s HIV prevention efforts (table 12). A further $7 million was allocated by the Department for International Development (DFID UK).
<table>
<thead>
<tr>
<th>International organization</th>
<th>Provincial counterpart</th>
<th>Project title</th>
<th>Timeframe</th>
<th>Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UNICEF</strong></td>
<td>YAPCO</td>
<td>Yunnan AIDS Prevention, Control and Care</td>
<td>1996–2000</td>
<td>RMB 16.54 m ($2 million)</td>
</tr>
<tr>
<td></td>
<td>YCDC</td>
<td>Yunnan Women’s Federation Training on HIV/AIDS Control and Care</td>
<td>1999–2000</td>
<td>RMB 534,000</td>
</tr>
<tr>
<td><strong>ADB /UNDP</strong></td>
<td>YAPCO</td>
<td>Yunnan AIDS Prevention, Control and Care</td>
<td>1997–1998</td>
<td>RMB 827,000 ($100,000)</td>
</tr>
<tr>
<td><strong>Amity Foundation</strong></td>
<td>YAPCO</td>
<td>Yunnan AIDS Prevention, Control and Care</td>
<td>1998–2000</td>
<td>RMB 3.23 m (DM 860,000)</td>
</tr>
<tr>
<td><strong>WHO</strong></td>
<td>YAPCO</td>
<td>Yunnan Pilot Sites for China’s Medium and Long-term Plan for AIDS Prevention and Control</td>
<td>1994–1996</td>
<td>RMB 2,646,400 ($320,000)</td>
</tr>
<tr>
<td><strong>UN-ESCAP</strong></td>
<td>YIDA</td>
<td>Community-based Drug Abuse and HIV/AIDS Prevention</td>
<td>1991–1998</td>
<td>RMB 661,600 ($80,000)</td>
</tr>
<tr>
<td><strong>Save the Children (UK)</strong></td>
<td>Department of Education of Yunnan</td>
<td>School-based AIDS Prevention Education &amp; Puberty Health Ed Developing Training Programmes for SWs and IDUs in Ruili Development Centre for Women and Children Education</td>
<td>1996–2000</td>
<td>RMB 1,550,625 (125,000 BPS)</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>RMB 210,000</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>RMB 240,000</td>
</tr>
<tr>
<td><strong>Ford Foundation</strong></td>
<td>Yunnan Reproductive Health Research Association</td>
<td>‘Healthy Lives’ Project for Middle School Students Gender and AIDS Survey of Women in Fumin County on AIDS KAP Peer Education on AIDS Prevention among Students in Kunming Medical School</td>
<td>1998–1999</td>
<td>RMB 20,000</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>RMB 50,000</td>
</tr>
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<td></td>
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<td></td>
<td>RMB 3,000</td>
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<td></td>
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<td></td>
<td></td>
<td>RMB 9,000</td>
</tr>
<tr>
<td><strong>Oxfam (HK)</strong></td>
<td>YIDA</td>
<td>Peer Education on Harm Reduction among IDUs</td>
<td>1999–2000</td>
<td>RMB 93,000</td>
</tr>
<tr>
<td><strong>The Salvation Army (HK)</strong></td>
<td>YCDC</td>
<td>HIV/AIDS Prevention Education Training for Women Carers in 16 Prefectures</td>
<td>2000</td>
<td>RMB 23,000</td>
</tr>
<tr>
<td><strong>MSF Holland</strong></td>
<td>YAPCO</td>
<td>HIV/AIDS Awareness Campaign in Yunnan Province</td>
<td>2000</td>
<td>RMB 80,000</td>
</tr>
<tr>
<td><strong>Australian Red Cross</strong></td>
<td>Yunnan Red Cross</td>
<td>Youth Peer Education on HIV/AIDS Prevention</td>
<td>1996–2000</td>
<td>RMB 6 million</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td></td>
<td>RMB 33.4 million</td>
</tr>
</tbody>
</table>

YAPCO = Yunnan AIDS Prevention and Control Office
YCDC = Yunnan Child Development Centre
YIDA = Yunnan Institute for Drug Abuse
Excludes DFID funds of $21 million for China, of which $7 million was for Yunnan.
Current and projected impact on child well-being

Macro-level impact

The official macro-level data presented in the following table do not indicate any particular impact on children in Yunnan, the province with the highest prevalence of HIV. There are as yet no significant differences between the national data on children’s well-being and Yunnan’s aggregate data, but that may change as prevalence rises.

Table 13. Summary data of child well-being in China and Yunnan province

<table>
<thead>
<tr>
<th></th>
<th>90</th>
<th>95</th>
<th>99</th>
<th>00</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant mortality rate</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>50.2 (91)</td>
<td>36.4</td>
<td>33.3</td>
<td>32.2</td>
</tr>
<tr>
<td>Yunnan</td>
<td>66.4</td>
<td>53.1</td>
<td>37.1</td>
<td>33.1</td>
</tr>
<tr>
<td>Under 5 mortality rate</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>61.0 (91)</td>
<td>44.5</td>
<td>41.4</td>
<td>39.7</td>
</tr>
<tr>
<td>Yunnan</td>
<td>87.3</td>
<td>66.9</td>
<td>46.6</td>
<td>42.1</td>
</tr>
<tr>
<td>Percentage of infants with low birth weight (under 2,500 grams)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>5.9 (98)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yunnan</td>
<td>—</td>
<td>3.5</td>
<td>3.5</td>
<td></td>
</tr>
<tr>
<td>Percentage of children under 5 suffering from moderate–severe wasting</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>8</td>
<td>5</td>
<td>3 (98)</td>
<td></td>
</tr>
<tr>
<td>Yunnan</td>
<td>29.0</td>
<td>17.7</td>
<td>15.9</td>
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</tr>
<tr>
<td>Percentage of children under 5 suffering from moderate–severe malnutrition</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>China</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yunnan</td>
<td>25.7</td>
<td>25.5</td>
<td>23.9</td>
<td>22.4</td>
</tr>
<tr>
<td>DPT3 immunization coverage</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>China</td>
<td>97</td>
<td>92</td>
<td>97</td>
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</tr>
<tr>
<td>Yunnan</td>
<td>93.1</td>
<td>85.0</td>
<td>95.4</td>
<td>97.6</td>
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<tr>
<td>Measles immunization coverage</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>China</td>
<td>98</td>
<td>93</td>
<td>98</td>
<td></td>
</tr>
<tr>
<td>Yunnan</td>
<td>95.0</td>
<td>85.0</td>
<td>95.3</td>
<td>97.8</td>
</tr>
<tr>
<td>Percentage of mothers receiving prenatal health checks</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Yunnan</td>
<td>12.7</td>
<td>55.5</td>
<td>81.4</td>
<td>82.9</td>
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<tr>
<td>Percentage of births attended by skilled health personnel</td>
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<tr>
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<td>59.6</td>
<td>82.3</td>
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<td>Primary school female net enrolment</td>
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<td></td>
<td></td>
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<tr>
<td>China</td>
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<td>98.2</td>
<td>99.0</td>
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</tr>
<tr>
<td>Yunnan</td>
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<td>98.8</td>
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</tr>
<tr>
<td>Primary school male net enrolment</td>
<td></td>
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</tr>
<tr>
<td>China</td>
<td>99.2</td>
<td>98.9</td>
<td>99.1</td>
<td>99.1</td>
</tr>
<tr>
<td>Yunnan</td>
<td>97.6</td>
<td>98.2</td>
<td>99.2</td>
<td>99.1</td>
</tr>
<tr>
<td>Pupil–teacher ratio</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>21.9</td>
<td>23.3</td>
<td>23.1</td>
<td>22.2</td>
</tr>
<tr>
<td>Yunnan</td>
<td>25.7</td>
<td>25.5</td>
<td>23.9</td>
<td>22.4</td>
</tr>
</tbody>
</table>
Children orphaned by AIDS

There will be increasing numbers of children who are not HIV-positive themselves but one or both of whose parents die from an HIV-related illness. The magnitude of the problem will be less than in countries with higher fertility rates, but for China, a large number of children without either parent is unprecedented and will create internal difficulties where there are few specific policies and financial protections in place. Some provinces are, however, already taking steps: Henan province decreed that for such children living with their extended families, primary and secondary schooling would be free and there would be financial support for further studies (UNAIDS 2004).

**Figure 8. Children in Yunnan who have lost one or both parents due to AIDS**

Economic impact

As noted above, medical costs have escalated in recent years and this poses particular problems in Yunnan, which has not matched the national economic growth rates. For example, in the rural part of Ruili City, an average patient with HIV-related illness spends RMB 800 on medical treatment and RMB 2,500 on funeral costs, when the province’s average annual per capita income in rural areas was only RMB 1,478 in 2000. In fact, the income for those who are HIV-positive is likely to be below the provincial average, because studies have shown that, over a period of eight and a half years after diagnosis, PLHIV in Yunnan lost an average
of 87 working days to illness, and family members lost an average of 30 working days to care for them.

Those with HIV-related illnesses predominantly consult private, outpatient health care services (averaging 4.28 visits in the year preceding their death), as they are the least expensive (around RMB 40 or approx. $5 per consultation). If public health centres are used, preference is given to cheaper village facilities (RMB 10–20 or $1.21–2.42), over township health centres (RMB 100 or $12.50). The minority able to afford hospitalization (average 0.36 hospital visits for 77 PLHIV in their last year of life) stayed an average of three days, costing RMB 1,000–4,000 ($121–484).

In Yunnan, due to poverty and lack of economic access, many social services such as clinics, schools, kindergartens, water systems and training institutions, are underutilized. Those who are HIV-positive are even less able to avail themselves of the services, partly because of discrimination; for example, some schools refuse to enrol children from households with HIV-positive family members because they consider their families will not be able to pay for books and incidentals.

The micro-level impact of HIV on families and children is illustrated by the results of qualitative interviews with 31 households with HIV-positive family members in rural areas of Ruili. In the decade 1989–1999, Ruili reported a total of 794 HIV-positive cases, 411 (51.76 per cent) of whom died during this period (Zhang Jiapeng et al. 1999). Zhang Jiapeng and his group conducted qualitative interviews with 31 households with HIV-positive members. They were identified from records in the local epidemic prevention station. The main findings were as follows:

• The health of the HIV-positive family members had deteriorated, and 19 of them had developed HIV-related illnesses such as diarrhoea, fever, weight loss, coughing and skin ulceration. Their families felt helpless when the illness reached an advanced stage.

• Most families felt that their economic conditions were worse than families with no HIV-positive members, because they had to stay at home to take care of the patients 4–8 days per month. It was hardest for families with both husband and wife infected: they had to take drastic measures such as selling their land illegally or renting it out at a reduced price. Fourteen children from seven households dropped out of school to sell their agricultural produce.

• The PLHIV maintained a good relationship with their families, who in general cared about them and hoped they would recover. There was no obvious discrimination against HIV-positive family members within the household, but some of their neighbours appeared to be nervous and some of the children had been refused entry to school because their HIV-positive parents could not pay their tuition.
• Among the 21 infected couples, 2 wives returned to live with their parents and 5 spouses died of AIDS. Among the 14 couples who lived together, 6 used condoms under the instructions given by epidemic prevention centres, 6 did not use condoms and one husband used condoms only when he had sex with sex workers. The 14th person had no sex.

• Some continued using drugs, but most switched from heroin to opium, a few continued injecting heroin and sharing needles with other drug users.

• Among 16 wives, 4 had already taken the HIV test and 3 were then found to be HIV-positive. Of the remaining 12, 10 said they would not mind taking the test, but the other 2 said they would not want to do so.

What they feared most at the time of the interview was the onset of HIV-related illnesses, because they were too poor to pay for medical treatment. They worried about housing for their parents, wives and children and were afraid their children would suffer from discrimination, drop out of school, abuse drugs and become infected after their death.

Also, 10 per cent (3/31) were able to use village health centres and clinics, but most used private clinics for treatment because they were more convenient and cheaper (RMB 10–20 for each clinical visit). Three who were in more serious condition went to township health centres and paid approximately RMB 100.

The expected impact on children by the year 2010

It is estimated that by 2010 there will be a cumulative total of 16,000 children who have contracted the HIV virus from their mothers and there will be over 21,000 children under the age of 15 who will have lost one or both parents due to HIV.

Projected medical costs related to HIV

Predictions of potential medical costs for Yunnan are imprecise, given the number of variables, but based upon 2002 medical costs, and assuming that, of an estimated total of 1,982 HIV cases, 75 per cent in rural areas and 90 per cent in urban areas will seek medical treatment costing RMB 5,000, the costs (medical + funeral) for patients with HIV-related illness would reach a total of RMB 181 million in 2010.

Projected loss of GDP and rising poverty related to HIV

Medical and funeral costs contribute to GDP, but the loss of labour output will cause a fall in the rate. Combining the GDP gain from the medical and funeral sector with the loss due to both temporary and permanent non-participation in the labour market, the net loss to Yunnan’s GDP will rise to 0.43 per cent (RMB 828 million) in
2010 (assuming average growth of 4 per cent per year from 2000 to 2010). This is in line with the results of a World Bank study showing that low- and middle-income countries with serious HIV problems may experience a 0.5 per cent decline in GDP (Ainsworth and Over 1999).

### Table 14. Projection of number of children in Yunnan with at least one parent dead from an HIV-related illness

<table>
<thead>
<tr>
<th>Year</th>
<th>0–4 years old</th>
<th>5–9 years old</th>
<th>10–14 years old</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1991</td>
<td>11</td>
<td>0</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>1992</td>
<td>43</td>
<td>0</td>
<td>0</td>
<td>43</td>
</tr>
<tr>
<td>1993</td>
<td>96</td>
<td>0</td>
<td>0</td>
<td>96</td>
</tr>
<tr>
<td>1994</td>
<td>190</td>
<td>0</td>
<td>0</td>
<td>190</td>
</tr>
<tr>
<td>1995</td>
<td>339</td>
<td>0</td>
<td>0</td>
<td>339</td>
</tr>
<tr>
<td>1996</td>
<td>498</td>
<td>40</td>
<td>0</td>
<td>537</td>
</tr>
<tr>
<td>1997</td>
<td>682</td>
<td>121</td>
<td>0</td>
<td>802</td>
</tr>
<tr>
<td>1998</td>
<td>984</td>
<td>255</td>
<td>0</td>
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<tr>
<td>1999</td>
<td>1,335</td>
<td>483</td>
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<td>2000</td>
<td>1,637</td>
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<td>2001</td>
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<td>1,129</td>
<td>51</td>
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<tr>
<td>2002</td>
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<td>1,513</td>
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<td>4,190</td>
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<tr>
<td>2003</td>
<td>2,777</td>
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<tr>
<td>2004</td>
<td>3,169</td>
<td>2,944</td>
<td>585</td>
<td>6,699</td>
</tr>
<tr>
<td>2005</td>
<td>3,766</td>
<td>3,588</td>
<td>954</td>
<td>8,307</td>
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<tr>
<td>2006</td>
<td>4,474</td>
<td>4,354</td>
<td>1,332</td>
<td>10,160</td>
</tr>
<tr>
<td>2007</td>
<td>5,317</td>
<td>5,226</td>
<td>1,774</td>
<td>12,317</td>
</tr>
<tr>
<td>2008</td>
<td>6,317</td>
<td>5,854</td>
<td>2,661</td>
<td>14,832</td>
</tr>
<tr>
<td>2009</td>
<td>7,506</td>
<td>6,764</td>
<td>3,466</td>
<td>17,736</td>
</tr>
<tr>
<td>2010</td>
<td>8,918</td>
<td>8,037</td>
<td>4,184</td>
<td>21,140</td>
</tr>
</tbody>
</table>

An estimated 100,000 families will have at least one member living with HIV by 2010 and the incomes of at least 300,000 will be reduced below the poverty line (a 15 per cent increase) as the HIV-positive cases contract HIV-related illnesses.

### Medium-term measures

Control of HIV will require a significant increase in the quality and extent of government commitment and funding and the promulgation of specific relevant policies. In line with suggestions by the UN Theme Group on HIV/AIDS in China, recommendations for action in three areas are given below.
Mitigation of the effects of HIV infection: Due to the lack of access to health care discussed above, the HIV epidemic is unlikely to overwhelm the health services. It may, however, severely stretch the capacity of communities to cope. Solutions will require linkage to health care reforms, although these will probably not be able to deliver all the required services in the medium term. In the short and medium term, NGOs will need to run care projects in the worst-affected areas.

Needs assessment data from Yunnan indicate that medical staff have low levels of knowledge about HIV and opportunistic infections. Training in care, especially of opportunistic infections, would significantly improve the health situation.

The MoH has held discussions with pharmaceutical companies about the possibility of reductions in costs of antiretroviral drugs. However, it is unlikely this will lead to widespread access. Chinese production of generics would be feasible, but this is not currently an explicit objective of AIDS agencies.

Mitigation of poverty impact on HIV-infected/affected families: China’s success in reducing poverty is exemplary and hundreds of millions of families have been lifted out of poverty in the last decades. But there are no specific anti-poverty mechanisms for people with HIV. It will be essential in future to link the provision of HIV care work to the Bureaus of Labour, Social Security and Civil Affairs. Possible initiatives might include microcredit and child allowances, as well as occupational training.

Mitigation of the impact of HIV on the demand and supply of education: Chinese law stipulates that schooling is compulsory and should be free. However, schools charge user fees for books, school-related activities, etc. This amounts on average to RMB 300 per child per year in rural areas. Rural income in Yunnan is under RMB 1,600 per year, and in some villages as low as RMB 1,000. Given that many rural residents have two children, school fees would represent approximately half of a family’s annual income, even without losses due to HIV.

Orphan policy: Orphans are provided for by family and neighbours. The Ministry of Civil Affairs gives a small amount of support, based upon criteria for people living in difficulty (but not under the poverty alleviation effort). Although there are orphanages in Yunnan (including for the purpose of overseas adoptions), they are limited in number and scope and specific policies for children orphaned by AIDS have not yet been developed.

Stigmatization of people living with HIV: In order to reduce the heavy stigma against HIV and strengthen prevention programmes, PLHIV should be encouraged to join in broad community education efforts so that communities can learn from their personal experience.
**Prevention:** The overall levels of funding need to be increased and the funds allocated more efficiently if a significant impact is to be made on HIV. A great deal of work has been done in the areas of HIV surveillance and public awareness campaigning in Yunnan, but funding and policy support from the Yunnan Provincial Government still falls short of the actual amount required to control the rapid spread of HIV in the province.

Programmes to prevent HIV have hitherto worked on the assumption that an increase in knowledge will automatically result in a change in behaviour. But it is now recognized that in order to change behaviour there needs to be more concentration on attitudes and skills. However, the fact that some of the key risk groups for HIV infection (such as drugs users and SWs) are marginalized makes expanding such programmes particularly difficult. More use should be made of the media to raise public awareness. Projects such as promotion of 100 per cent condom use among SWs and homosexuals, methadone treatment programmes and needle exchange projects, as well as large-scale prevention of mother-to-baby transmission, are needed.

**Prevention of mother-to-child transmission:** Although infection from mother to child is an established route in Yunnan and elsewhere in China, most mothers are not aware of their status. Major constraints to limiting the transmission of HIV from mothers to children are:

1. The various levels of administration within the province (provincial, prefecture, county, township and village) are not well coordinated. This has implications for all six PMTCT interventions. Due to this lack of coordination, international organizations in Yunnan are finding it difficult to manage projects and standardize approaches.
2. The vast majority of people do not have access to confidential testing services.
3. The MCH (maternal and child health), FP and EPS (extended programme of surveillance) systems are uncoordinated at best and antagonistic at worst.
4. There is little, if any, MCH data collected or analysed at the county, township or village level (especially with regard to antenatal services, the cornerstone of PMTCT).
5. HIV treatment and care are poor at all levels.
6. Social support is virtually non-existent for PLHIV.

**Need for life skills education among vulnerable groups, especially young people:** International experience has taught that well-presented sex education in schools can become a powerful factor for convincing young people to engage in safer sexual behaviour and to postpone the start of their active sex life.
In China, traditional approaches to ‘education’ involve older people and people in authority lecturing young people about morality. Strategies that have elsewhere proven effective in HIV education, such as participatory education, youth-to-youth education, and developing decision-making skills have been practised very little. Numerous successful small-scale peer-education projects have repeatedly shown that this is a very appropriate teaching method in the Chinese context and this needs to be scaled up to those in middle school as well as young people out of school.

Furthermore, there is a great need to target minority populations with easy-to-read material in native languages and non-written messages through pictures, theatre, participatory drama, singing and dancing. Also important is enhancing minorities’ participation in the process of designing, implementing and evaluating prevention techniques.

**Urgent need for control of STIs:** The STI incidence needs to be tackled urgently and given priority attention nationwide, since international evidence indicates that the co-factor effect of STIs for promoting HIV spread is highest at the beginning of a sexual HIV epidemic. This will entail promoting modern and comprehensive public health systems to prevent and treat STIs.

**Policy and institutional measures**

Despite (and sometimes because of) legislative measures, STI/HIV prevention and care have made little progress in China, particularly at provincial and local levels.

- Institutional structures and practices make it hard for the central government to enforce laws and regulations and control situations locally.
- Many local governments do not want to research HIV in their area for fear that results will reflect poorly on the locality and its officials.
- Information flows slowly between village, county, provincial and national levels.
- The drug control policy is focused on supply and demand reduction through strict criminal punishment, causing drug users to fear seeking help. Harm reduction, which is the focus for HIV prevention, is not a priority.
- Several provincial and local laws are contradictory to the national MoH guidelines on treatment and care of patients with HIV-related illness. One of the Ministry’s guiding principles is ‘maintenance of confidentiality and the guarantee of individual legal rights’. The document says only that PLHIV should delay marriage and ‘seek a medical opinion’ before getting married. In November 2000, the Ministry issued another document stressing that HIV testing before marriage should be voluntary.
To summarize, there is a worrisome tendency towards restrictive and punitive lawmaking, despite the fact that international experience has shown restrictive laws have little effect on curbing the epidemic, and in actual fact can have clear-cut negative impacts on HIV prevention and care. Necessary measures include analysis of the effects of current policy as well as better monitoring of the implementation of national policy.

References and Bibliography


Notes


2 Estimation methodology of the National Center for AIDS Prevention and Control goes thus: in province x, 40,000 drug users (according to Public Security, which estimates that there are 10 times as many drug users who are not detained), of which 10 per cent have HIV (from Epidemic Station tests in selected sentinel sites of drug users detained) = 40,000 HIV+ drug users.
3 With the number of facilities doing HIV tests increasing, figures show an increase in the number of areas reporting HIV infections, following highway routes from the border. If each county or city is taken as one unit of reported infection, the number of infected units among the province’s 125 counties and cities (109 counties, 13 cities, 3 municipalities) in the 1989–2000 period was: 3 in 1989, 11 in 1990, 14 in 1991, 15 in 1992, 17 in 1993, 22 in 1994 and 36 in 1995; from there it jumped to 66 in 1996, and hit 99 in 1997; it continued to rise until it reached 102 in 1998, 111 in 1999, and 115 in 2000.

4 (1) Strengthening the antenatal care (ANC) system; (2) Voluntary counselling and testing (VCT); (3) Optimizing infant feeding practices; (4) Obstetric care; (5) Family planning (FP) counselling and services; (6) Antiretroviral therapy (ARV).
Introduction

The purpose of this chapter is to assess the impact of HIV and AIDS on economic growth in countries with different prevalence and economic structures and to suggest policy interventions to minimize the negative economic effects of this epidemic and avoid the widespread impoverishment of children in families infected or affected by HIV.

Economic growth and child welfare are simultaneously affected not only by HIV but also by other economic, military and social events, such as natural disasters, humanitarian conflicts and changes in terms of external trade. Disentangling the individual impact of each of these different effects is complex. It is possible – for instance – that the economic impact of HIV rises more than proportionately with the rise of prevalence. Also, it can be described as having ‘a long wave effect’, manifesting its impact after a time lag of 10 or even 20 years. Thus, countries where the epidemic is in its initial or intermediate stage feel a hardly perceptible impact on growth and poverty, and may therefore postpone the introduction of offsetting measures. Furthermore, the HIV phenomenon generates dynamic intersectoral and intergenerational effects that are not yet well understood or satisfactorily modelled. For instance, in Côte d’Ivoire, HIV prevalence rose initially in the urban sector but then gradually spread to the rural areas. In Yunnan (chapter 6), the epidemic developed initially among ethnic minorities but then spread among the dominant Han population. The impact of such shifts in prevalence on labour supply, aggregate growth, poverty, income distribution and public policy remains largely unexplored.

Economic impact of HIV: evidence from sectoral studies

The impact of HIV on the economy and child poverty is influenced by a variety of factors that change from country to country, but that always depend on prevalence...
(on average and by subgroups), the initial endowment of unskilled, semi-skilled and skilled labourers (teachers, doctors, managers, entrepreneurs), and changes in financial savings and capital accumulation. The economic impact also depends on whether or not production is based on highly specialized workers and on the modalities of saving formation, the existence of formal and informal health insurance, social safety nets and so on.

**Impact on production via a decline in labour supply and lower productivity**

The literature on the local-level impact of the HIV epidemic suggests that, as infection spreads among young and middle-aged workers, causing first illness and then, after a time lag of five to seven years, death, the total labour supply declines (ILO 1995). During the initial phase of the illness, the worker slowly starts losing his/her energy and productivity, due to a decline in body mass, energy, motivation and morale. This effect is not immediate, and an HIV-positive worker may carry on with a normal working life for some years after the onset of the infection. However, during the second phase, when AIDS has developed, there is nearly complete loss of work capacity and productivity. This stage can last up to two or three years, depending on the worker’s nutritional status and access to health care.

**Impact by skill level and sector of employment**

There is little data to show a variation in the incidence of disease by skill level. Although a survey of blood donors in Malawi found higher infection levels among skilled than unskilled ones, in Zambia, from 1984 to 1992, AIDS caused 62 per cent of deaths among managers, a rate that was slightly lower than the 71 per cent for lower-level workers (ILO 2000; Ching’ambo 1995).

In contrast, the incidence of HIV and the number of deaths among workers vary significantly according to the sector of employment, as a number of occupational groups show higher than average rates of infection. Among them are those whose job entails considerable spatial mobility or interpersonal contacts, such as contract and transport workers, miners, fishermen, sales representatives and seasonal workers in agriculture, construction and tourism. Jobs that convey social status and power – as in the case of security personnel, teachers, health workers and wealthy managers – also exhibit higher than average rates of infection (ILO 2000). A survey of drivers in East Africa revealed an average infection rate of 33 per cent. And in one Zambian hospital, deaths among staff increased 13 times between 1980 and 1990, mainly because of AIDS. In the Kagera region of the United Republic of Tanzania, 55 health workers died of AIDS between 1987 and 1993; the increase was so pronounced that other health workers refused to be posted there. According to the South African Medical Research Council, approximately 25 per cent of miners are HIV-positive, while the AIDS Society believes the true figure to be nearer 45 per cent. A recent study of Carletonville, the centre of South Africa’s gold industry, found that 60 per cent of women under 25 were infected (ILO 2000).
High levels of infection were also found on many commercial farms (FAO 1999a; Haslwimmer 1994). In Zimbabwe, in 1996, one major transport company with 11,500 workers found that 3,400 of them were HIV-positive (Whiteside 2000).

**Impact on the rural labour force:** The effects of HIV on agricultural growth are most immediate, as in this sector there are generally few possibilities for substituting a dwindling supply of labour with capital. Lack of skilled labour obliged farmers of several West African countries to delay some activities and, consequently, to obtain reduced yields (Black-Michaud 1997). On a Kenyan sugar estate, the spread of HIV among the wage labourers led to a 50 per cent drop in sugar output between 1993 and 1997 (ILO 2000). Between 1979 and 1991, per capita production fell in Mozambique (-3.1 per cent), United Republic of Tanzania (-1.4 per cent) and Uganda (-0.6 per cent) (Ruigu 1995).

The impact of HIV on farm productivity is also indirect. The care of sick relatives, participation in funerals and the sale of equipment following an HIV-related death contribute to a reduction in the labour supply and the productivity of uninfected workers. In Zimbabwe, an agricultural extension worker estimated that funerals took up to three days a month, or 10 per cent of his working time (Ncube 1999). In Zambia, an adult in an affected household loses 952 hours a year in personal sickness, with even more time needed for the care of the sick and funerals. In contrast, those in unaffected households take an average 518 hours off for personal sickness and 300 hours for care of the sick and attending funerals (Bangwe 1997). In Namibia, 25 per cent of the production time in critical periods was lost due to mourning alone (Engh et al. 2000). And Tibaijuca (1997) found that in the Kagera region of the United Republic of Tanzania, 81 per cent of the respondents felt that hired labour was difficult to find, and wages increased tremendously over the decade.

HIV also affects long-term rural growth, as it interrupts the transmission of farming knowledge across generations (du Guerny 1999). Barnett’s (1994) study on Uganda, United Republic of Tanzania and Zambia confirms that mortality seems to have a greater impact than morbidity in rural areas, not only because of labour loss, but also as a result of the termination of farming knowledge.

**Responses by farmers to the impact of HIV:** Farmers adopt a series of adjustments to respond to the decline in their workpower. In a first phase, they may increase the family labour supply. In Zambia, heads of households in HIV-affected families responded to loss of workpower among adults by teaching and supervising male teenagers to take over the fields. The spontaneous pooling of community labour resources is another way in which farmers have their land farmed, despite rising HIV infection within their family.

Some affected households grow less labour-intensive crops. Studies of African smallholders find that affected families in Uganda substituted resource-intensive cash crops – such as coffee or tomatoes – for less labour-intensive crops such as
cassava (Topouzis 1994; Mutangadura et al. 1999a; Rugalema 1999; du Guerny 1999). Similar strategies were employed in the communal agricultural systems of Zimbabwe (Kwaramba 1997) and in the north of Côte d’Ivoire (Black-Michaud 1997). The death of an income earner may lead to a decline in purchased inputs and the sale of draught power and farm implements to cover medical and funeral expenses (Ncube 1999). When these adjustments prove insufficient, the affected households reduce crop cultivation, especially in outlying fields.

These adjustments can generate a permanent economic impact due to a decline in soil fertility. As shown in a number of studies, agricultural practices such as regular weeding and maintenance of irrigation systems may be neglected. In extreme cases, food plantations have reverted to the wild. In the commercial sector of Kenya, much of the fertile land of families hard hit by the epidemic remains idle due to labour shortages (Rugalema 1999). Waller’s (1996) study on the impact of farming in the Monze district of Zambia shows that the poorest households reduced the cultivated area and 10 out of 15 of them reverted to zero-tillage. Land fertility may be affected over the long term by a drop in the use of fertilizers. In Zambia, 90 per cent of farmers had either stopped using fertilizer altogether or reduced the quantity below the recommended amount (Waller 1996). The livestock sector also suffers in that there is an increase in the morbidity/mortality of animals and fewer livestock products. In Gweru, some cattle died or were stolen when they could no longer be herded properly (Ncube 1999).

**Impact on the urban labour force:** The impact of HIV on the skilled urban labour force may be less immediate – because of greater possibilities of substitution of labour with capital – but HIV-related deaths cause greater damage, as the possibility of replacing highly skilled workers is generally lower and its costs higher. A study of enterprises in South Africa found that fewer than 40 per cent of the employers believed they had a good chance of replacing skilled workers (ILO 2000). And rapid turnover means loss of valuable experience as happened in the Uganda Railway Corporation. Absenteeism is another problem. Studies of businesses in East Africa show that it accounts for between a quarter and a half of the HIV/AIDS cost because of the disruption of the production cycle, underutilization of equipment and the cost of hiring temporary staff (ILO 2000).

**Impact on savings and capital accumulation**

Another impact of HIV on growth is through a slowdown in the formation of public and private savings and their investment in productive capital. Such impact is not straightforward and is scarcely documented. While public savings and infrastructure are likely to diminish – because of the increased pressure on current expenditure – the impact on household savings and firm profits is more difficult to predict and is likely to depend on the extent to which the additional health and welfare expenditures are borne by the households concerned or by the public sector.
In principle, HIV should raise the pressure to increase household savings (for future health care, funerals and obligatory bequests) while at the same time reducing them (due to impoverishment and increased current health costs).

The evidence reviewed in chapter 8 and the country case studies seems to suggest that the additional costs incurred through the spread of HIV were mainly covered by the households in low-income countries and by the state budget in the middle-income ones. The Monze study on farming households shows that 33 per cent of the households studied felt that high medical fees cut into farming investments, particularly for livestock (Waller 1996).

A study on Benin (UNDP 1998) records a fall in savings in 84 per cent of the 68 families with a member employed in the formal sector who died of AIDS. The study of the Rakai district in Uganda by Menon et al. (1997) shows that the households affected by an HIV-related death lost their savings and were forced to sell their properties to pay for health care and funeral expenditures to a greater extent than households affected by other types of death.

As for earnings, a study of female traders in the Owino market in Uganda shows how quickly they can lose their livelihoods. The majority of market women trade in perishable goods (vegetables, fish, fruit, cooked food), that require short turn-around time: business collapses when women attend to the sick for long periods. Moreover, many have had to forfeit their stalls in the market and are unable to resume trading after their personal savings have been depleted (Sentongo 1995). An ILO (1999b) workshop came to the conclusion that many of the HIV-infected workers in the informal sector can no longer afford their premises, so their businesses collapse. And in Zimbabwe, the households studied lost half a million Zimbabwean Dollars in earnings during the 1997–1998 agricultural season because of their inability to cultivate their land (Ncube 1999).

**Impact on earnings and profits for commercial enterprises**

Given a fixed supply of labour for each skill category, HIV may have the effect of increasing wages and enterprise costs (e.g. for health insurance) and – assuming competitive product markets – of compressing profits, but this effect ought to be much less pronounced in countries with an excess labour supply.

In many countries, commercial farms suffer sharp cuts in output and profits as a result of the loss of workers and decreased working hours due to illness, death, stress, attendance at funerals and home care of ill dependants. In the United Republic of Tanzania and Zambia large urban sector companies reported that HIV-related health costs surpassed their total annual profits, while in Botswana, large companies estimated that HIV-related costs would increase from under 1 per cent to 5 per cent of the wage bill in six years (ILO 2000).
In Zambia, in 1993, the medical expenses incurred by the INDENI Petroleum Refinery were 1.2 times the net profits, and millions of Kwacha were paid to relatives of ill employees in the form of basic salaries and funeral grants (Ching’ambo 1995). Similar findings are reported from Zimbabwe (Guinness and Alban 2000) and Botswana and Kenya (Roberts and Rau 1995; Bollinger and Stover 1999, p. 4).

The impact on profits may, however, be offset by restructuring that reduces the legal obligations of companies to their workers. In Tanzania, the Economic Recovery Programme allowed organizations to get rid of employees living with HIV (Moshi 1995). Kad’iebwe’s (1995) study of the impact of HIV on the labour force in Rwanda from April 1992 to March 1993 shows that the immediate dismissal and replacement of middle and senior personnel was common.

Impact on consumption

Although families reduce their savings, sell assets and borrow from friends and relatives, the decline in income due to HIV invariably results in lower consumption levels. This can permanently affect the welfare of children and their families, particularly when essential expenditures, such as food and schooling, are reduced.

But this fall in consumption may be temporary. Béchu (1998) shows that urban households of Côte d’Ivoire where a person infected with HIV died showed a 28 per cent fall in per capita consumption of basic needs, but consumption recovered during the following year, so the overall reduction amounted to 12 per cent. Janjaroen’s (1997) analysis confirms these findings in the case of Thailand. Lundberg et al. (2000) suggest that the lower income group affected by HIV experience a 30 per cent fall in food expenditure over the short term.

In urban areas of Côte d’Ivoire, the proportion of the household budget spent on health care is 10.6 per cent for people affected by HIV and 5.6 per cent for people affected by other illnesses (Béchu 1998). UNAIDS (2000) shows that, in these areas, families reduced their outlay on education by half, while average spending on health care went up four times. Likewise, Over et al. (1989) found that in Kagera, United Republic of Tanzania, health-care expenditures were 8 per cent of annual household expenditures in those affected by HIV, and 0.8 per cent in those not affected.

Impact on government expenditure

Another impact of HIV arises from the need to increase government expenditure on health, teacher training and welfare transfers, while tax revenue is declining. This can lead to growing budget deficits and, eventually, to the adoption of restrictive adjustment policies. Alternatively, if the deficit is covered through public bonds, it can lead to higher inflation or a rapid accumulation of public debt.

Though there are few convincing analyses in this area, it may well be that – except
for economies counting on large mineral rents (as in Botswana) – tax revenue may de-
cline because of the slowdown in economic activity induced by HIV. Much will depend
on the sector affected the most, whether it is the urban (and more easily taxable) sector
or the rural and informal sector that generally contributes less to state taxes. Meanwhile,
it is likely that non-HIV-related expenditure on health, education, the training of teach-
ers, nurses, food subsidies, and other social programmes may fall. As noted, health and
social welfare systems are being affected by a surge in health spending on HIV and
pressures to introduce orphan and other allowances. This may in turn affect mortal-
ity/morbidity and other aspects of child well-being in communities unaffected by HIV.

Assessment of the overall impact of HIV on the economy

Many of the studies reviewed above are local-level analyses (often based on a
small number of observations), the results of which cannot necessarily be extrap-
olated to the national level. Moreover, the analyses do not examine the systemic ef-
fects. The overall impact of HIV is therefore assessed below through studies that
rely on different approaches.

Microeconomic approach: estimating the impact on a sample
of HIV-affected families

Some studies try to assess the economic impact of HIV by computing the loss of
household income and the greater medical and other costs incurred over a given pe-
riod of time by the families affected by HIV, in relation to unaffected families with
similar socioeconomic characteristics. Such an approach normally calls for iden-
tification of a representative sample of HIV-affected households and an equally
representative control group; measurement of the average income loss and higher
costs incurred by the HIV-affected family in relation to the control group; actual-
ization of all income losses and greater costs at one point in time; and extrapola-
tion of the ‘unit cost of HIV per affected family’ to the total number of families
affected by HIV at that point in time, divided by GDP.

Anand et al. (1999) assess the total annual cost of HIV for the period 1986–
1995 in India under different (low, medium and high) estimates of HIV prevalence.
The total annual cost of HIV includes: the loss of productivity among patients with
HIV-related illness due to sickness and death; HIV caregivers’ loss of productiv-
ity; and the cost of management of patients with HIV-related illness. The loss of
output due to HIV is estimated in rural and urban areas separately, through a life
table approach, using two cohorts, one with and one without HIV: the difference
in person-years lived between the two scenarios is then converted into monetary
terms by means of the national per capita income for 1992–1993. The loss of pro-
ductivity among working, but enfeebled, patients with HIV-related illness is esti-
mated by relying on current data and expert opinion. An HIV-positive person is
assumed to need six hospital admissions for HIV-related illnesses before death, for an estimated total of 100–200 hospital days. The study concludes that the estimated annual cost of HIV ranges between 0.1 per cent and 1.1 per cent of GDP, depending on the assumption made about prevalence.

This kind of study could be improved in some respects. It would make sense to disaggregate the economy into its rural and urban components, as incomes, hospitalization rates, care patterns and so on differ substantially between the two. Moreover, these analyses are static, as the surveys are taken at one point in time and cannot therefore capture the interaction between the impact of HIV (on labour supply, income, consumption, etc.) and the subsequent reactions by the families and communities affected. The studies only provide a partial analysis of the phenomenon at hand, as they reflect the changes that occur in the HIV-affected sector, but not their interaction with the rest of the economy. Another drawback is what may be termed the micro–macro inconsistency or aggregation bias. In extrapolating income losses from the micro to the macro level, it is assumed that all workers are fully occupied, but this is seldom the case. In reality, an income loss at the micro level, although it results in the severe impoverishment of a family, may cause no perceptible contraction in GDP because the loss of output due to the death of a worker is made up by a previously unemployed one taking his or her place. The aggregate impact may also change because of the adoption of policies facilitating the substitution of labour with capital.

Macroeconomic approach

Another approach to the estimation of the impact of HIV is to build partial equilibrium or computable general equilibrium (CGE) models, in which GDP is a function of the stocks of production factors (physical capital, land, labour and human capital) that are, in turn, eroded by HIV in a variety of ways. The most prominent of such models are discussed below:

(i) Kambou et al. (1992) built one of the first detailed CGE models to assess the impact of HIV in Cameroon. The model is calibrated on the years 1979–1980 and includes a multisectoral production function that captures intersectoral interactions through prices and demand effects. It also includes a detailed treatment of the government and household sectors. On the production side, there are three categories of labour (rural, urban-skilled and urban-unskilled) that cannot be substituted for each other, while investment is driven by domestic savings. The world demand and prices for Cameroonian exports and the net capital inflows remain unchanged and government expenditure is constant.

This model is closer to the real world than most other studies reviewed in this chapter, but its conclusions are affected by problems. First, as in all CGE models, the structural parameters are not estimated econometrically, but are assigned values derived from the literature that are then ‘calibrated’ to make the model reproduce the correct
value of the dependent variables. Such a procedure has obvious limitations. Furthermore, the calibration is carried out with reference to 1979–1980, when the HIV prevalence was very low and AIDS had not manifested its impact. Also, as in most other studies reviewed, no allowance is made for excess labour supply. The model is also not ‘dynamic’ in that it is a sequence of static models obtained by updating variables over time, a fact that does not capture the cumulative effects of the relation between HIV and the economy, and makes no difference between the different stages of HIV and AIDS. Finally, the model assumes there are no financial assets, while it is plausible that one of the main impacts of HIV is precisely via the financial sector.

(ii) Over (1992) built a model to estimate the impact of HIV on the growth of GDP per capita in 30 African countries over the period 1990 to 2025, under alternative assumptions about the distribution of the epidemic and the financing of the costs it generates. The author represents the growth process using two generalized Cobb–Douglas production functions, one for the rural sector (making use of unskilled labour and farmable land, the supply of which expands at a given annual rate) and one for the urban sector (making use of skilled labour and capital). The capital stock in the urban sector rises in line with the yearly gross investment, i.e. total foreign and domestic savings. The labour force in each year is disaggregated into six groups, according to educational achievement and sector of work. The risk of contagion rises with the workers’ level of education, which means that the loss of labour is greater in an economy with more educated workers. The cost of treating HIV is also assumed to rise steeply in line with the level of education. The model shows that, when a proportion of the cost of treating HIV is financed from private savings, the negative impact on growth of GDP is greater. The model’s main conclusion is that raising the share of the treatment cost financed from savings, or assuming that the epidemic affects productive workers more, increases the negative impact on income growth. Overall, HIV is shown to depress GDP growth rates by some 0.33 per cent a year.

(iii) In 1994, Over produced a model with Ainsworth to assess the impact of HIV on per capita income, through changes in the capital output ratio, the cost of HIV treatment to per capita income, and the proportion of the treatment costs financed from savings. The extent of the economic impact is determined by prevalence and incubation period. They assume that the national output is produced through work and capital, that HIV has an incubation period ranging between 5 and 10 years, and that a country has a steady HIV prevalence of 10 per cent. Every 10 per cent increase in the epidemic slows the growth of the workforce by 0.6–1.0 per cent a year. About half of the costs for HIV treatment are financed through savings; this results in reduction of the growth rate of capital accumulation. These assumptions lead to the conclusion that the fall in the growth rate of per capita income ranges from 0.1 per cent if the national prevalence is 10 per cent and the incubation period is 10 years, to 0.8 per cent if the prevalence is 30 per cent and the incubation period five years. Despite its pioneering nature, the model is too aggregate and somewhat simplistic.
Another macro CGE study on the impact of the HIV epidemic in South Africa is that by Arndt and Lewis (2000), who built a disaggregated economy-wide simulation model including 14 sectors, 5 production factors, 5 households quintiles, and 10 government expenditure categories. The estimates of labour supply, AIDS and non-AIDS death rates and HIV prevalence are derived from the extrapolations of Quattek (2000). AIDS deaths are assumed to affect the economy by reducing the workers in each skill class proportionately, while HIV-positive workers are half as productive as non-affected workers. The model’s simulations show that the GDP growth rate declines gradually over time, to reach a maximum fall of 2.6 per cent in 2008. The result, however, suffers from shortcomings similar to the other CGE models discussed above.

A non-CGE model by BER (2001) also attempts to quantify the macro impact of HIV in South Africa during the period 2000–2015, with the main emphasis being on sensitivity analysis rather than precise point estimates. As do other models for South Africa, it makes use of the Actuarial Society of South Africa (ASSA) model for all demographic projections for population groups by age, gender, skill and area. It estimates that a fall in the population and labour force efficiency would lead to a 21 per cent reduction in productivity. Secondly, greater costs to the business sector for pension, disability and medical benefits would add 5 per cent to the skilled employee wage bill by 2005 and double that by 2010. Companies would pass on 50 per cent of this cost in prices and absorb the rest through a cut in profits. The business sector would also bear higher costs for recruitment and training as well as absenteeism and lower staff morale that would reduce productivity by up to 40 per cent. The Government would have to increase expenditure, taxes and the deficit, while cutting public health expenditure in the non-HIV sector, and doubling it for HIV in order to employ additional health staff and purchase health inputs for those affected. More funds would be needed for fostering children orphaned by AIDS. At the household level, families would have to finance half their additional HIV-related expenditures from personal savings and half by reducing purchase of goods and services. The model forecasts that GDP will be 1.5 per cent lower by 2010 and 5.7 per cent lower by 2015, i.e. values that are somehow lower than those estimated in other studies.

The BIDPA (2000b) study on the impact of HIV in Botswana makes use of household and individual data from a 1993/4 survey. The study predicts that by 2010, 49 per cent of households will have at least one infected member, 7 per cent will have disappeared and 26 per cent will lose income as a result of the death of a family member.

The analysis evaluates the impact of HIV on income and expenditures over a 10-year period (by which time HIV-infected people are expected to have died), assuming a 5.7 per cent reduction in the overall unemployment rate and a 12.2 per cent increase in the wages of skilled workers (but not of the unskilled ones). The additional medical and funeral expenditures are estimated on the basis of discussions
with general practitioners and are included among the household expenditures. Households are assumed to spend an additional 25 per cent of their income on each person infected with HIV. The study predicts an 8 per cent fall in income per capita and a 5 per cent rise in the number of the people living in poor households, with no change in income inequality, but an increase in the dependency ratio. The situation of the first quartile of households is the worst, as their income and dependency ratios deteriorate more than the average. The introduction of medical and funeral expenditures does not change the income levels but does increase the incidence of poverty. However, the model results depend on too many assumptions, a fact that makes the estimate of the HIV impact too hypothetical.

(vii) In the Quattek (2000) model, the impact of HIV on each sector depends on the mix of workers between unskilled workers (who have infection rates of 30 per cent and are assumed to cause no additional costs as they are less likely to be covered by health and other benefits) and skilled and highly skilled workers, who are proportionately less affected by HIV (their infection rates reach 23 per cent and 13 per cent respectively) but have a high replacement cost. Transport, storage, catering and accommodation are the sectors most exposed to the HIV epidemic, while machinery, communication and metals fare relatively better, and service industries such as finance and business rank in the middle. The impact of HIV is estimated by assuming a work loss of four months per person-year, weighted by skills, for every person diagnosed with AIDS.

The model estimates that between 2006 and 2015, GDP would rise an average 0.3–0.4 per cent a year and domestic savings would be 2 per cent less than in the absence of HIV, while the consumer price index would increase due to higher interest rates and cost pressures on companies. However, capital-intensive technologies would sustain investment.

(viii) Nicholls et al. (2000) model the macroeconomic impact of HIV for Trinidad and Tobago and Jamaica. They assume a three-sector economy (agriculture, industry and services) with a Cobb–Douglas production function and male and female labour markets for all three sectors. Domestic savings are proportional to income and finance all investments but are affected negatively by expenditures on AIDS drugs, HIV tests and hospitalization. In this model, HIV prevalence rises by 20 per cent between 1997 and 2005. The simulation leads to the conclusion that GDP in Jamaica and Trinidad and Tobago would decline by an average 6.4 per cent and 4.2 per cent respectively. These estimates may seem excessive, since the cost of treating HIV has significantly declined, and there are no dynamic changes in dependency ratios or investments in human capital.

(ix) Cuesta (2001) builds a partial equilibrium model for Honduras that includes a Cobb–Douglas production function. The model simulations assume alternative HIV and AIDS incidence rates, while all other variables are kept constant in real
terms. The simulation of 10 alternative scenarios with different levels of HIV incidence, financing of HIV treatment and environmental conditions suggests that the growth impact ranges between 0.7 per cent and 2.7 per cent a year, and is mainly due to the negative impact on labour availability rather than on capital accumulation.

In conclusion, although the CGE and partial equilibrium approach gives an adequate representation of the structural relationships between an economy and the direct and indirect effects of HIV, it does suffer from a few shortcomings: It provides estimates that depend on a large set of assumptions and tend to be country specific, even when sensitivity analysis is carried out; CGE models are usually not estimated econometrically and offer few insights into the impact of the epidemic across sectors or social groups; and the models are limited in their simulations of policy interventions in the field of health care financing, orphan allowances and accelerated formation of production factors.

Cross-country regressions

This class of model examines the relationship between changes in GDP growth rates in countries affected by different HIV prevalence and AIDS death rates at one point in time, or over a period of time, after controlling for as many variables as possible. One such study is that by Bloom and Mahal (1997), who dismiss the claim that HIV reduces the growth of the economy, on the basis of cross-country regression analysis for 51 countries between 1980 and 1992 and 1987 and 1992. The study shows that, over both periods, the negative relationship between economic growth and the rise in HIV prevalence is a spurious one, explained by the fact that HIV increased most in countries with low income per capita. The authors conclude that the HIV epidemic has had an imperceptible effect on the growth rate of GDP and per capita income.

However, these strong conclusions are weakened by a number of technical and theoretical problems. The HIV and AIDS data utilized in the study come from different, and possibly inconsistent, sources. Also, both periods analysed had a low number of AIDS cases, even when HIV prevalence started to rise. The impact of AIDS and HIV on GDP and GDP per capita tends to be quite different, so that the overall impact may change over time. It is not clear from the model whether HIV affects the economy, through a decline in the labour force, the differential spread of the epidemic in rural and urban areas, diversion of scarce public expenditure to the prevention and treatment of HIV, or other factors.

In a cross-sectional study of some 70–80 low- and middle-income countries from 1990 to 1997, Bonnel (2000b) comes to rather different conclusions and suggests that, while in low-prevalence countries the growth impact is negligible, for Africa as a whole, the growth of per capita income was reduced by 0.7 percentage points a year. In the words of the author, in the absence of HIV, ‘Africa’s income per capita would have grown at 1.1 per cent a year – as opposed to the 0.4 per cent
achieved from 1990 to 1997’. A country with a 20 per cent HIV prevalence would see its per capita GDP growth rate drop by 2.6 per cent a year.

Cross-country regressions are subject to a number of criticisms. While both studies cited above tried to include all the necessary variables, it is not clear that they succeeded in accounting for all the factors that may affect growth, and/or HIV prevalence. Neither study allows for any time lag between the rise of HIV prevalence and the impact on GDP growth. The use of period averages over several years for both per capita income growth and HIV prevalence conceals the cumulative effect of rising prevalence on GDP growth. Neither study takes into account the fact that the impact of HIV on growth depends on whether or not labour is fully employed, and that the effect of HIV varies according to the sector and level of labour skills involved. In the Bonnel (2000b) study, there is no empirical support for the proposition that the HIV impact on growth depends on the effectiveness of policy and regulations.

**Regressions on panel data**

Econometric analyses conducted on panel data are in principle able to correct for several of the methodological problems encountered in cross-country regressions and to best capture the impact of HIV on economic growth, even if such impact may have been quite modest until recently in several countries.

Dixon et al. (2001) try to assess the impact of the HIV epidemic on growth by means of an econometric model, covering 41 African countries over the period 1960 to 1998. The model predicts a reduction of 1.3 per cent in economic growth at an HIV prevalence of 20 per cent. This growth reduction is about half that estimated by Bonnel (2000). Dixon’s model is, however, highly aggregated and misses some of the real life interactions between HIV and the economy. It assumes full employment of all the labour force and does not allow for the existence of a labour surplus that would nullify the impact of the loss of skilled workers. Moreover, the model makes no distinction between HIV and AIDS. In addition, it suffers from a few estimation problems, as some of the coefficients (on education and health capital) are not significant, or indicate the wrong correlation between variables.

Table 1 summarizes the main results of the studies reviewed above in terms of the impact of HIV on GDP growth. These results are not immediately comparable, as they sometimes refer to rather different assumptions about HIV prevalence, and in some cases reflect the influence of specific country situations. But the studies summarized in table 1 do suggest a few important conclusions: First, the impact of HIV tends to be imperceptible in countries with HIV prevalence of less than 3–4 per cent. Second, most studies suggest that a mature epidemic (5–20 per cent and above) can reduce the growth rate by 0.5–1.0 GDP growth points a year, an impact that is certainly costly when it is sustained over the medium and long term. Finally, the studies that refer to the entire economy generate GDP impact results that are substantially
lower than those derived from local surveys in the country case studies, where it appears that an affected family loses some 30–40 per cent of its income. This means that in countries – such as Botswana – where HIV prevalence exceeds 35 per cent, GDP should have declined by some 10.5–14 percentage points, a result that is at variance with both the studies reviewed above and empirical observation.

Table 1. Summary of the annual reduction in GDP growth rate per year due to HIV identified in studies based on macro, micro, cross-country and panel data

<table>
<thead>
<tr>
<th>Country</th>
<th>Reference</th>
<th>Average reduction in annual GDP growth rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>India</td>
<td>Anand et al. (1999)</td>
<td>0.1–1.0</td>
</tr>
<tr>
<td>Cameroon</td>
<td>Kambou et al. (1992)</td>
<td>1.9</td>
</tr>
<tr>
<td>South Africa</td>
<td>Arndt and Lewis (2000)</td>
<td>1.4–2.6</td>
</tr>
<tr>
<td>South Africa</td>
<td>BER (2001)</td>
<td>0.1–0.9</td>
</tr>
<tr>
<td>A representative African country</td>
<td>Ainsworth and Over (1994)</td>
<td>0.1–0.8</td>
</tr>
<tr>
<td>South Africa</td>
<td>Quattek (2000)</td>
<td>0.3–0.4</td>
</tr>
<tr>
<td>Botswana (a)</td>
<td>BIDPA (2000b)</td>
<td>8 (over 10 years)</td>
</tr>
<tr>
<td>Botswana</td>
<td>Jefferis and Greener (1999)</td>
<td>1–2</td>
</tr>
<tr>
<td>Trinidad and Tobago</td>
<td>Nicholls et al. (2000)</td>
<td>4.2 (over 8 years)</td>
</tr>
<tr>
<td>Jamaica</td>
<td>Nicholls et al. (2000)</td>
<td>6.4 (over 8 years)</td>
</tr>
<tr>
<td>Honduras</td>
<td>Cuesta (2001)</td>
<td>0.7–2.7</td>
</tr>
<tr>
<td>A representative sub-Saharan African country</td>
<td>Over (1992)</td>
<td>0.15–0.33</td>
</tr>
<tr>
<td>United Republic of Tanzania</td>
<td>Cuddington (1993a)</td>
<td>0.10</td>
</tr>
<tr>
<td>Malawi</td>
<td>Cuddington and Hancock (1994)</td>
<td>0.25</td>
</tr>
<tr>
<td>51 developing and industrialized countries</td>
<td>Bloom and Mahal (1997)</td>
<td>Insignificant</td>
</tr>
<tr>
<td>70–80 low- and middle-income countries</td>
<td>Bonnel (2000b)</td>
<td>1.20 (in case of prevalence of 20%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.80 (as in SSA, prevalence 8%)</td>
</tr>
<tr>
<td>41 African countries</td>
<td>Dixon et al. (2001)</td>
<td>1.30 (in case of prevalence of 20%)</td>
</tr>
</tbody>
</table>

Note: (a) National household income.
A simple model of the impact of HIV on GDP growth

This section develops a simple aggregate model, described formally in Annex 1, which tries to overcome some of the inconsistencies found in the models outlined above. The model has the following features:

i) It separates agriculture (A) and all ‘other sectors’ (O), such as industry, services and the public sector, that are assumed to be located only in urban areas, while excluding the possibility of migration between A and O. The different epidemiological patterns in the urban and rural sector and their shifts over time can thus be represented.

ii) It allows for two different production technologies; in agriculture, production depends on unskilled labour (U) and arable land, while in the ‘other sectors’ it depends upon physical capital (K), skilled labour (S) and unskilled labour.

iii) It shows ‘labour surplus’ for both skilled and unskilled workers, so that the death of a worker in a labour surplus area causes family impoverishment but not aggregate effects on GDP because the vacated job can immediately be filled by an unemployed worker.

iv) It computes the decline in the output of one sector (e.g. the rural sector) caused by the HIV-induced decline in purchases from it by the other (e.g. urban) sector. This means that growth rates in A and O are both supply and demand driven.

v) It allows for the emergence of public deficits incurred by governments to finance a rise in medical and social welfare expenditure. Over the medium term, such deficit is not seen as harmful to growth.

vi) It makes private saving (and therefore capital accumulation) in both A and O an inverse function of HIV prevalence.

vii) HIV reduces land and labour productivity in A and labour and capital productivity in O, while AIDS reduces the employed workforce in both A and O except in case of labour surplus.

viii) It represents the dynamics of HIV prevalence with a logistic function and that of the cumulative AIDS deaths with a similar function. Table 3 describes prevalence determined by the model at periods 0 and 3 under different assumptions about \( z \).

The data sources used to benchmark the model are: the World Development Indicators (2001) for the GDP growth rates in 50 relevant countries; ILO (2000) for the projected labour force with and without HIV; and FAO (1999b) for the worldwide estimates of the agricultural population and labour force during the period 1950–2010. Finally, the values of the parameters used for the simulation of the model were drawn from the literature summarized in table 2.
<table>
<thead>
<tr>
<th>Parameter</th>
<th>Value</th>
<th>Country, estimate and reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>$\lambda_A$ output elasticity of unskilled labour in agriculture in land rich and poor countries</td>
<td>0.3 or 0.7</td>
<td>Cornia et al. (1996) and Over (1992)</td>
</tr>
<tr>
<td>$\kappa_A$ output elasticity of the land in land rich and land poor countries</td>
<td>0.7 or 0.3</td>
<td>Cornia et al. (1996)</td>
</tr>
<tr>
<td>$\lambda_O$ output elasticity of unskilled labour in the urban sector</td>
<td>0.3</td>
<td>0.3 Cornia et al. (1996) and 0.4 Over (1992)</td>
</tr>
<tr>
<td>$\kappa_O$ output elasticity of the productivity of capital in the ‘other activities’ sector</td>
<td>0.3</td>
<td>0.3 Cornia et al. (1996) and 0.2 Over (1992)</td>
</tr>
<tr>
<td>$\eta_O$ output elasticity of skilled labour in the ‘other activities’ sector</td>
<td>0.4</td>
<td>Cornia et al. (1996) and Over (1992)</td>
</tr>
<tr>
<td>$m^Y_A$ average propensity to consume in the rural sector</td>
<td>0.8</td>
<td>World Development Indicators (2001)</td>
</tr>
<tr>
<td>$m^Y_O$ average propensity to consume in the urban sector</td>
<td>0.8</td>
<td>Cornia et al. (1996)</td>
</tr>
<tr>
<td>$n_A$ share of consumption exp. allocated to agricultural products by the rural pop.</td>
<td>0.8</td>
<td>World Development Indicators (2001)</td>
</tr>
<tr>
<td>$n_O$ share of consumption expenditures allocated to ‘other activities’ by urban pop.</td>
<td>0.6</td>
<td>Cornia et al. (1996)</td>
</tr>
<tr>
<td>% labour force in A</td>
<td>Not used</td>
<td>from 3.1 in Botswana to 92.4 in Burkina Faso World Development Indicators (2001) (a)</td>
</tr>
<tr>
<td>% GDP accounted for by A</td>
<td>Not used</td>
<td>from 2.5 in Trinidad and Tobago to 60.8 Guinea-Bissau, World Development Indicators (2001)</td>
</tr>
<tr>
<td>$l^Y_A$ impact coefficients of HIV on the productivity of unskilled rural labour</td>
<td>0.1</td>
<td>South Africa 0.08 Morris et al. (2000)</td>
</tr>
<tr>
<td>$k^Y_A$ impact coefficients of HIV on land fertility</td>
<td>0.1</td>
<td>Côte d’Ivoire 0.1 (land) Black-Michaud (1997) Uganda, United Republic of Tanzania, Zambia 0.1 (land) Barnett (1994) Uganda 0.06 (livestock) Haslwimmer (1994)</td>
</tr>
<tr>
<td>$l^Y_O$ impact coefficient of HIV on the productivity of unskilled urban labour</td>
<td>0.1</td>
<td>Uganda, United Republic of Tanzania, Zambia 0.02 Barnett (1994) Zambia 0 Ching’ambo (1995) South Africa 0.02–0.05 BER (2001)</td>
</tr>
<tr>
<td>$k^Y_O$ impact coefficient of HIV on the productivity of capital in ‘other activities’</td>
<td>0</td>
<td>Uganda, United Republic of Tanzania, Zambia 0 Barnett (1994) Zambia 0 Ching’ambo (1995)</td>
</tr>
<tr>
<td>$h^Y_O$ impact coefficient of HIV on the productivity of skilled urban labour</td>
<td>0.1</td>
<td>South Africa 0–0.02 BER (2001)</td>
</tr>
</tbody>
</table>

The model is sufficiently broad to depict a good number of situations but at the same time is simple enough to be estimated on panel data. However, it is unable to capture several impacts of HIV described in the literature, such as those mediated by the erosion of social capital, the rise in the number of children orphaned by AIDS and the worsening of income distribution. Other limitations of the model concern its inability to allow for the lack of technological progress (e.g. the discovery of an HIV vaccine) or government interventions (for instance in the field of prevention and treatment) that would affect the HIV prevalence trend and cumulative AIDS deaths over time. Also, the model does not explicitly incorporate the public sector and budget deficit or the external sector (imports, exports, balance of payment, foreign aid, investment and debt).

Preliminary results

The basic scenario shows that, for any time and reasonable set of HIV prevalence, among skilled and unskilled workers in rural and urban areas, the economic impact of the cumulative AIDS deaths is greater than that of the increase in HIV prevalence. This means that the economic impact of the epidemics is somewhat ‘delayed’, and that in most countries affected by AIDS, the main effect of the epidemic is still to be felt (as in South Africa, chapter 4). Second, the strongest impact of AIDS deaths and HIV-related diseases occurs between the period during which HIV prevalence rises the fastest, and when it reaches its maximum. Third, once the relative importance of agriculture and of the ‘other sectors’ in GDP is taken into account, the growth impact estimated by the model is consistent with the results of the aggregate economy-wide models reviewed earlier. Fourth, the impact on GDP growth depends less on the relative prevalence across sectors, and more on the relative productivity of the different factors. Thus, the economic impact of HIV is greater in the urban sector as productivity is highest among the urban skilled worker, followed by urban and rural unskilled workers. Fifth, the economic impact of the epidemic is non linear, i.e. it rises more than proportionately for any increase in prevalence.

Four main measures were tested for the impact of policy interventions. The first scenario assumes that the government bears all health expenditures to prevent a reduction in the household saving rates. The second simulates a policy of accelerated training of scarce skilled workers so that their depletion rate is reduced and growth sustained. A third scenario assumes that public policy will use activities such as training to ensure that a labour surplus in one sector can fill a gap in another. The fourth scenario assumes that antiretroviral treatment is provided to workers so as to reduce the HIV impact on economic growth. The main results of the simulations can be summarized as follows:

i) Avoiding the impact of HIV on savings and capital formation by subsidizing additional expenditure on health and social welfare is the most effective policy in any scenario. In table 3, when HIV prevalence does not affect the saving rate in rural or urban areas (see column where mVA = mVO = 0.8), reductions in the growth rates of GDP are always consistently smaller than those when the
additional HIV-related expenditures increase average consumption \((m^V_A = m^V_O = 1.0)\) and reduce savings to zero. Policy decisions on the financing of additional HIV-related expenditure therefore not only have an enormous impact on the well-being of the sick, but also on national growth, especially in countries with weak or non-existent financial markets.

ii) The accelerated training of urban skilled workers is an effective policy to sustain growth only if labour productivity in agriculture is low. And accelerated training of additional rural unskilled workers \((z_{US} \text{ and } z_U = 0.2, \text{ with } z_r = 0.1)\) would lead to a smaller reduction in GDP growth \((9.3-6.4 = 2.9)\). However, if labour productivity in the agricultural sector is high \((l_A = .7, \text{ results not shown})\) – as is the case in rural Africa – increasing the supply of urban skilled workers would slow the GDP decline less than the training of rural unskilled workers.

iii) The introduction of measures promoting flexibility (by skill, gender, age and location) in the deployment of labour and facilitating substitution between different kinds of labour, reduces excess demand for the most effective and scarcest kind of labour, and so avoids large output reductions.

<table>
<thead>
<tr>
<th>Prevalence among rural, urban and urban unskilled workers</th>
<th>(l_A = .3, \ k_A = .7, \ l_o = .3, \ k_o = .3, \ h_o = .4)</th>
<th>(m^{V_A} = m^{V_O} = 0.8)</th>
<th>(m^{V_A} = m^{V_O} = 1.0)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(z_R) (z_U) (z_{US}) (t) (A) (O) (A) (O)</td>
<td>(z_R) (z_U) (z_{US}) (t) (A) (O) (A) (O)</td>
<td>(z_R) (z_U) (z_{US}) (t) (A) (O) (A) (O)</td>
<td>(z_R) (z_U) (z_{US}) (t) (A) (O) (A) (O)</td>
</tr>
<tr>
<td>0.0 0.0 0.0 0 0.0 0.0 47.2 47.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.2 0.2 0.0 0 7.3 16.3 57.0 67.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.1 0.1 0.1 0 4.7 18.8 53.6 70.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.2 0.2 0.1 0 8.3 26.9 58.4 80.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.0 0.2 0.2 0 3.4 35.7 51.8 90.4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.1 0.2 0.2 0 6.4 36.3 55.8 91.4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.2 0.2 0.2 0 9.3 37.0 59.7 92.3</td>
<td></td>
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<tr>
<td>0.0 0.0 0.0 3 0.0 0.0 47.2 47.1</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>0.2 0.2 0.0 3 12.3 32.1 66.8 91.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.1 0.1 0.1 3 9.8 45.9 62.7 109.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.2 0.2 0.1 3 15.0 60.4 70.8 130.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.0 0.2 0.2 3 7.5 78.0 58.5 154.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.1 0.2 0.2 3 13.1 79.2 67.6 156.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.2 0.2 0.2 3 16.9 80.0 73.8 158.2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Authors’ calculations.

Notes: For the explanation of \(l_A\), \(k_A\), \(l_o\), \(k_o\), \(h_o\) see table 2. The parameters \(z_R\), \(z_U\), \(z_{US}\) set to 0 represent a situation of surplus for rural, urban and urban skilled workers; \(m^{V_A} = m^{V_O} = 0\) describes the case in which HIV prevalence does not affect the saving rates in rural and urban areas.
Policy responses

What are the possible policy responses to sustain growth and avoid distributive distortions and mass impoverishment in countries affected by HIV and AIDS? To answer this question, it is important to underline once more the fact that, unlike other shocks, such as recessions or terms of trade crises, HIV and AIDS are a long wave, not temporary phenomena, that exert a cumulative effect on the functioning of the economy. A second characteristic of HIV and AIDS is that they erode the stocks of the production factors (skilled and unskilled labour, land fertility, financial savings, investments and social capital). Finally, HIV and AIDS tend to cause considerable distributive distortions and increase poverty. Accordingly, recommendations for possible policies to sustain growth and avoid poverty in the AIDS era are outlined below:

Avoid a decline in the stock of production factors

Avoiding a decline in the stock of available labour should be a primary policy concern of HIV-affected countries. This can be achieved through prevention activities in all sectors and at all levels, as discussed in chapters 7 and 8. In view of the large costs imposed on them by HIV, firms should also be more proactive than in the past in the field of prevention, counselling, testing and treatment of STI and opportunistic infections. ARV treatment is also crucial. There are strong human rights arguments for gradually expanding such treatment to all infected people; and purely from a cost-benefit perspective, the replacement cost of many workers (for their upbringing, education and acquisition of on-the-job experience) can be much higher than the cost of generic ARV drugs.

Consequently, the health policy suggestion is that, if only a small fraction of the population can be treated, the focus should be on skilled workers, though as soon as it is possible to expand the programme, treatment should be made available to workers in different sectors, with varying skills, to avoid possible supply bottlenecks. Should the treatment of existing workers be impracticable, the training of potentially scarce skilled workers should be accelerated. Enterprises and governments should provide budgetary support to facilitate the training or importation of technicians, specialized workers and other categories of labourers in short supply. This applies to people in vital positions, entrusted, for instance, with the task of ensuring the functioning of power grids, water and railway systems, health and education, highly specialized industries and so on. Targeted interventions in some of these sectors can generate important positive effects and prevent a slowdown of growth.

In the long term, the negative impact of HIV needs to be counterbalanced by ensuring that enrolments in primary and secondary education are sustained through measures, discussed in detail in chapter 9, such as curriculum simplification, the
waiver of enrolment fees, special provisions for the education and training of a mounting number of orphans, and so on.

Compensating for the decline in household savings and enterprise profits – and the ensuing drop in investments – is more problematic. Here, too, good policies can make some difference. The review of the literature in this chapter, and the model simulations presented above, suggest that state financing of a substantial part of the additional HIV-related health and welfare expenditure may limit the decline in household saving, enterprise profits and private investments. If the initial public debt/GDP ratio is low, governments can finance their HIV-related deficits by issuing state bonds. International transfer of resources – in the form of budgetary support or international investments – is also a way of sustaining capital accumulation. At the individual level, improvements in financial markets, such as making credit available at affordable rates, could help to support output among families, whether or not they are affected by HIV.

**Promote greater flexibility in the use of production factors**

Another possible response – at the community and enterprise level – would be to focus on measures to facilitate the mobility of production factors. There is already scattered evidence that communities affected by the virus adopt a less rigid division of labour by skill level, age and gender and encourage labour pooling arrangements, thus promoting greater flexibility in labour deployment and efficiency. This could be encouraged through incentive schemes and would help to avoid production bottlenecks.

In countries such as Botswana and South Africa, where the infection rate among skilled and unskilled workers is very high, and wages have been rising, the large mineral rents may facilitate a change towards capital-intensive rather than labour-intensive technology.

**Sustain individual/community responses to preserve welfare and local economies**

When faced with economic adversity, extended families and traditional societies have for long relied on well-tested and efficient informal arrangements to sustain consumption and avoid long-term economic decline. When faced with a loss of income, families generally begin by rationalizing consumption, increasing the supply of labour (with females, the elderly, or children) or migrating. The next step is to liquidate financial savings and other assets and adjust the family structure. When these measures are no longer sufficient, they revert to damaging measures such as the sale of productive assets (oxen, land, tools), the reduction of essential expenditures on health and basic food, the withdrawal of children from school and the adoption of risky behaviour (exploitative work, sex trade and crime).
For their part, communities undertake collective action (pooling labour) in production, while seeking collective economies of scale in consumption (as in the case of the Peruvian *comedores populares*, or for child care). Communities also rely on local informal insurance and assistance mechanisms. Such activities work well in short-term emergencies, but in high-HIV-prevalence countries are insufficient to avoid both a decline in well-being and shrinkage of the economic base of families and communities. There are several indications that such family and community strategies are increasingly unable to weather the economic and social impact of HIV, so they need to be scaled up with external support and complemented by other broader measures.

**Employment-based programmes:** HIV impoverishes not only the person infected but also – through demand, supply and systemic effects – those with links through family, employment, trade or exchange. One way of counteracting these systemic effects is to introduce employment-based programmes with the dual purpose of sustaining the incomes of the families and communities over the medium term and avoiding a deterioration of the economic base (physical infrastructure, expertise etc.) of the community.

Employment-based programmes can effectively reach the needy but able people of working age. Several arguments justify the adoption of public work schemes, which not only permit the achievement of specific poverty alleviation objectives over the short run, but also contribute to productivity growth over the long term by speeding up the accumulation of capital, or avoiding its deterioration. There is already considerable experience with the design and management of such programmes. Successful examples include the Maharastra Employment Guarantee Scheme (later replicated throughout India as the Jawahar Rozgar Yojana), Chile’s Minimum Employment Programme and Occupational Scheme for Heads of Households (that in 1984 covered 40 per cent of the jobless) or Botswana’s Labour-Based Relief Programme. These programmes have been successful in offsetting the impact of recessions and droughts but now need to be adjusted to the situation of HIV-affected communities, a situation in which the pandemic tends to reduce the labour power of some (but not all) segments of society.

**Microcredit and training programmes:** Employment-based programmes are not suitable for poor families that have no surplus labour to employ. In this case, interventions could include measures to increase the productivity and earnings of the declining amount of labour power already employed. This can be achieved through microcredit or skill-upgrading programmes. Training in activities where new skills generate quick returns (especially in the urban sector), as well as greater access to funds, enhance the ability of families and communities to respond to crises.

There is a vast literature on the design and management of such programmes, including in HIV-affected countries such as those of south-eastern Africa. Obviously,
such credits create short-term liabilities and are therefore not suitable for persons with AIDS, who are likely to be sick, weak and depressed, but they should be attractive to their family members. Such microcredit is not granted for long periods – so HIV-positive people unaware of their status may participate in such community-based schemes that often combine welfare and economic support into one single intervention (chapter 8).

Income transfer: Such programmes not only avoid unnecessary suffering, but also prevent the adoption of destructive survival strategies, such as the sale of productive assets and the withdrawal of children from school. Such measures are necessary for those families that cannot be helped through employment-based, microcredit or training programmes.

Insurance or assistance-based transfer programmes have been in existence in low- and middle-income countries for some years, but are generally underdeveloped in the countries affected by HIV. The standard Western model of social security is of little applicability to low-income HIV-affected countries for cost and organizational reasons. Yet, there are examples in low-income rural settings of low-cost, non-contributory, state-funded schemes, providing coverage in old age, sickness, disability, widowhood and situations that cannot be tackled by increasing access to employment. The Kerala and Tamil Nadu non-contributory old age pension schemes, for instance, cover almost all the elderly poor, while some form of social assistance is available to the physically handicapped, the victims of work injury and half the workers in the informal sector. An estimated 17 per cent of poor households in Tamil Nadu are covered by this programme, and nearly 60 per cent of the beneficiaries are poor women. It is estimated that the extension of such a minimum social assistance package to all similar poor households in India would cost only 0.3 per cent of the national GDP (Guhan 1992).

Income transfers can be targeted directly or indirectly to HIV-affected children, through orphan and/or foster care allowances, basic pensions for the elderly – who are often in charge of a number of orphans – as well as to impoverished people sick with HIV. Such transfers can be in kind (food/clothing), in cash (books/school meals/transport allowances) and exemptions from school and medical fees. Elements of such schemes are in existence in several HIV-affected countries. In Botswana, in 2000, the Government introduced a monthly ‘package’ of $60-worth of subsidies in kind for children orphaned by AIDS. South Africa has instituted a child support grant, a foster care allowance and a care dependency grant for children with severe problems (chapter 4). Thailand has developed a mixed system in which temple-based and community-based transfers are complemented by central government interventions targeted at children (chapter 5). Even financially stretched countries such as Zambia have considered a modest transfer system (worth $0.5 million a year) to offset school costs for children orphaned by AIDS.
(personal communication of UNICEF Zambia). These programmes should be expanded, better analysed and evaluated. Particular attention needs to be placed on key design issues, such as the value of the transfer, the target population (whether all children in HIV-affected families, children orphaned by AIDS, or all orphans), the disbursement channels (the municipal and local authorities, the NGOs or the communities) the institutional arrangements, and other considerations, including accountability and potential problems of stigma for beneficiaries.

References and Bibliography


Annex 1

Model structure

In the absence of policy measures to control it, the dynamics of HIV prevalence can be depicted by a non-linear function that can be meaningfully assumed to be a logistic function. The AIDS death rate \( D(t) \) rises with a time lag of one period (of seven years) in relation to the HIV prevalence \( V(t) \):

\[
\begin{align*}
L(t) & = \frac{\rho t}{1+\rho t} \\
D(t) & = \frac{\rho t'}{1+\rho t'}
\end{align*}
\]

The model assumes that HIV epidemiological patterns are likely to vary in different areas of the country and therefore introduces a distinction between HIV prevalence in rural and urban areas. For sake of simplicity, the model assumes that, for each time \( t \), the impact of HIV-related diseases and AIDS deaths in rural areas is a proportion of those in urban areas. Let \( z_R \) and \( z_U \) be the parameters attached to \( V(t) \) and \( D(t) \) to represent the HIV and AIDS dynamics in rural and urban areas, respectively:

\[
\begin{align*}
L_{,R}(t) & = z_R \frac{\rho t}{1+\rho t} \\
D_{,R}(t) & = z_R \frac{\rho t'}{1+\rho t'} \\
L_{,U}(t) & = z_U \frac{\rho t}{1+\rho t} \\
D_{,U}(t) & = z_U \frac{\rho t'}{1+\rho t'}
\end{align*}
\]

The impact of HIV-related diseases and AIDS deaths on the economy is likely to be different in different sectors, so that their aggregate impact depends on the relative importance of these two sectors in the country considered. In this model, the rural economy is devoted only to the production of agricultural goods and the urban economy is involved only in the production of all ‘other sectors’ so that the labour force in agriculture and the ‘other sectors’ is taken to be the rural and urban active population.

The impact of HIV-related diseases and AIDS deaths is also likely to differ according to the skill level of the labour force. To make things easier, the model assumes that in each time period \( t \) the impact of HIV-related diseases and AIDS deaths on skilled workers is a multiple \( z_{RS} \) and \( z_{US} \) of that on the unskilled workers where the subscripts \( RS \) and \( US \) refer to rural skilled and urban skilled workers. As a result, the impact of HIV and AIDS on skilled and unskilled workers in the urban and rural sector can be written as follows:

\[
\begin{align*}
L_{,RS}(t) & = z_{RS} \frac{\rho t}{1+\rho t} \\
L_{,US}(t) & = z_{US} \frac{\rho t}{1+\rho t} \\
L_{,U}(t) & = z_U \frac{\rho t}{1+\rho t} \\
L_{,S}(t) & = z_S \frac{\rho t}{1+\rho t}
\end{align*}
\]

The growth process is depicted using two generalized Cobb–Douglas production functions, one for the rural and one for the urban sector. In agriculture, growth depends on the availability of unskilled labour and land, while in the ‘other sectors’ it depends on skilled and unskilled workers and the capital stock. Let \( L_A, K_A, L_O, K_O \) and \( H_O \) be the amount of unskilled workers, land, physical capital and skilled
workers respectively involved in agriculture and the ‘other sectors’ and \( l_A, k_A, l_O, k_O \) and \( h_O \) be their coefficients in the relevant production functions.

As for the impact of the pandemic on production, the model assumes that the HIV-related diseases reduce the productivity of unskilled workers, land, capital and skilled workers. Let \( l^{\nu}_A, k^{\nu}_A, l^{\nu}_O, k^{\nu}_O, h^{\nu}_O \) be the coefficients through which the spread of HIV affects the productivity of these factors of production. For simplicity, we assume that the productivity of capital in the ‘other sectors’ declines in line with the spread of HIV among the skilled workers only. Thus, the level of GDP in the agricultural and ‘other sectors’ is given by:

\[
Y_A = l_A^{l_A} K^{l_A} (l_A^{l_A} K^{l_A})^{-l_A^{l_A}} \quad Y_O = l_O^{l_O} K^{l_O} (l_O^{l_O} K^{l_O})^{-l_O^{l_O}}
\]

The impact of AIDS deaths on production is to reduce the amount of unskilled and skilled workers. As the model does not contemplate the possibility of migration between sectors, the impact of AIDS mortality on agriculture and the ‘other sectors’ is given by:

\[
I_A(t) = -z_R \cdot I_A(t) \quad I_O(t) = -z_U \cdot I_O(t)
\]

where these two relations depict the reduction in the number of workers available in agriculture and the ‘other sectors’, while

\[
H_A(t) = -z_S \cdot H_A(t) \quad H_O(t)
\]

represent the reduction in human capital due to the death of experienced staff in the ‘other sectors’. Notice that setting \( z_R, z_U \) and \( z_US \) equal to 0 allows to simulate a situation of labour surplus for both skilled and unskilled workers. As for capital accumulation, the model assumes that there are no foreign investments and that capital formation in both agriculture and the ‘other sectors’ depends only on the savings generated within each of these two sectors. Let \( m_A \) and \( m_O \) be the average shares of GDP devoted to private consumption in rural and urban areas. HIV-related diseases increase such propensities to consume. Let \( 1-m_A \) and \( 1-m_O \) be the saving rates in rural and urban areas, and let \( m^{\nu}_A \) and \( m^{\nu}_O \) be the coefficients through which the HIV dynamics affect these saving rates. The model assumes that the saving rate in urban areas depends on HIV prevalence among unskilled workers. Thus the changes in capital stock in agriculture and the ‘other sectors’ are given by:
\[
K_{A}(t) - Y_{A}(t) - m_{A} l_{A}(t) - m_{A} m'_{A} l'_{A}(t) Y_{A}(t) - d_{A} K_{A}(t)
\]

\[
K_{O}(t) - Y_{O}(t) - m_{O} l_{O}(t) - m_{O} m'_{O} l'_{O}(t) Y_{O}(t) - d_{O} K_{O}(t)
\]

Assuming that \(d_{A} = d_{O} = 0\) allows to solve explicitly for:

\[
I_{A}(t, K_{A}(0), Y_{A}(t), m_{A}, m'_{A})
\]

\[
I_{O}(t, K_{O}(0), Y_{O}(t), m_{O}, m'_{O})
\]

Assuming then that \(L_{A}(0) = L_{O}(0) = H_{O}(0) = 1\) (i.e. standardizing the initial values of these variables to 1), the changes in GDP in agriculture and the ‘other sectors’ can thus be written as the log transformation of the GDP levels. Therefore, the HIV and AIDS impact on the change of GDP in these two sectors is given by:

This allows to obtain explicit solutions for:

\[
Y_{A}(t) = \left(1 - l_{A} - l'_{A}\right) Y_{A}(0) + k_{A}(1 - k_{A}) K_{A}(t) - (l_{A} l_{A} + k_{A} k_{A}) Y_{A}(t)
\]

\[
Y_{O}(t) = \left(1 - l_{O} - l'_{O}\right) Y_{O}(0) + k_{O}(1 - k_{O}) K_{O}(t) + T_{O}(t) + (l_{O} l_{O} + k_{O} k_{O}) Y_{O}(t)
\]

in which the world demand for, and prices of, national products and the net capital inflows remain unchanged. Finally, the model defines

\[
g_{A}(t) = Y_{A}(t) - Y_{A}(0)
\]

\[
g_{O}(t) = Y_{O}(t) - Y_{O}(0)
\]

as the growth rates of output in agriculture and the ‘other sectors’. Finally, let us assume that \(Y_{A}(0) = Y_{O}(0) = 1\) and that \(n_{A}\) and \(n_{O}\) are the proportions of consumption expenditures allocated to agricultural products by the rural population and to other products by the urban population. This allows to take into account the negative impact on the growth of each of the two sectors of the decline in the demand originating in the other sector. Thus, the supply and demand impact of HIV and AIDS on growth rates of the sectoral GDP is given by:

\[
g_{A}(t) = (1 + n_{A} H_{A}) g_{A}(t) + \left[m_{A} (1 - n_{A})\right] g_{A}(t)
\]

\[
g_{O}(t) = (1 + n_{O} H_{O}) g_{O}(t) + \left[m_{O} (1 - n_{O})\right] g_{O}(t)
\]
Chapter 8
Poverty and HIV: Impact, Coping and Mitigation Policy
Tony Barnett and Alan Whiteside

Introduction
There is a huge and – 20 years into the epidemic – disgraceful lacuna in what we know about HIV and poverty, both the ways that the epidemic exacerbates poverty and the reverse. Families and communities have had to respond through necessity, but in most cases their responses, described as ‘coping’, have gone undocumented. In fact, very little is known about the more general relationship between infectious disease and poverty. With regard to HIV and poverty, little is known at the analytical level, and even less is known, at least to academic and agency personnel, about the policy and practical implications. Even where there is information, we need to recognize that we are only 20 years into what will be a long wave event, whose effects will be felt for generations to come. Compared to an epidemic of influenza, HIV is a very long wave event. The true death toll cannot be estimated until the full wave form of the epidemic has been seen. It may be as long as 30 more years before we can say that the world epidemic has peaked and/or begun to decline. If we take into account the social and economic impacts of the epidemic, in particular HIV-related impoverishment, then the epidemic and its impacts can be considered as an event that will last as long as a century.

HIV deepens poverty and increases inequalities at every level: household, community, regional and sectoral. The epidemic undermines efforts at poverty reduction, income and asset distribution, productivity and economic growth. HIV has reversed progress towards international development goals because of the influence it has on all development targets.

Responses to the epidemic seem to chase rather than lead it. Apart from persistent fear, denial and stigma, there is still lack of clarity on biological, social, economic and development relationships and HIV, and what is known may be poorly implemented. While prevention must remain a priority, the reality is that the impact of the disease must be mitigated. AIDS has already become the number one cause of death in many parts of the world and the impacts due to illness, death and orphanhood are in fact just beginning.
The relationship between poverty and HIV

There is an undoubted relationship between poverty and the development of epidemics of communicable diseases. At the same time, epidemic diseases – like any illness – have the potential to increase poverty.

Stillwagon has recently convincingly argued ‘that HIV prevalence is highly correlated with falling calorie consumption, falling protein consumption, unequal distribution of income and other variables conventionally associated with susceptibility to infectious disease, however transmitted’ (Stillwagon 2000). The causal chain runs from macro-factors that result in poverty: through the community, the household, the individual and into the resilience of the individual’s immune system. Work in cell biology has shown that the mechanisms that connect malnutrition and parasite infestation depress both specific and non-specific immune responses by weakening epithelial integrity and the effectiveness of cells in the immune system (Stillwagon 2000). Protein-energy malnutrition, iron deficiency anaemia, vitamin A deficiency, all of these poverty-related conditions decrease resistance to disease in general and to HIV in particular.

Figure 1 shows some of the general relationships. Each column is an area where policy interventions can be hypothesized and tested. The shaded columns are those where poverty-based interventions are appropriate.

**Figure 1. Proximal and distal ‘causes’ of HIV**

<table>
<thead>
<tr>
<th>Determinants</th>
<th>Distal determinants</th>
<th>Proximal determinants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Macro-environment</strong></td>
<td><strong>Micro-environment</strong></td>
<td><strong>Behaviour</strong></td>
</tr>
<tr>
<td>Wealth</td>
<td>Mobility</td>
<td>Rate of partner change</td>
</tr>
<tr>
<td>Income distribution</td>
<td>Urbanization</td>
<td>Prevalence of concurrent partners</td>
</tr>
<tr>
<td>Culture</td>
<td>Access to health care</td>
<td>Sexual mixing patterns</td>
</tr>
<tr>
<td>Religion</td>
<td>Levels of violence</td>
<td>Sexual practices and condom use</td>
</tr>
<tr>
<td>Governance</td>
<td>Women’s rights and status</td>
<td>Breastfeeding</td>
</tr>
<tr>
<td><strong>Interventions</strong></td>
<td></td>
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<tr>
<td>Social policy – redistribution</td>
<td>Social policy</td>
<td>Behaviour change communication</td>
</tr>
<tr>
<td>Legal reform – human rights</td>
<td>Economic policy</td>
<td></td>
</tr>
<tr>
<td>Taxation</td>
<td>Legal reform</td>
<td></td>
</tr>
<tr>
<td>Debt relief</td>
<td>Employment legislation</td>
<td></td>
</tr>
<tr>
<td>Terms of trade</td>
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</tbody>
</table>

Poverty contributes to epidemic disease and epidemic disease contributes to poverty: causation is bidirectional and occurs through many different pathways. For example, loss of labour from a farming system may result in failure to maintain infrastructure such as terracing, leading to soil erosion and decreasing agricultural productivity. This will impoverish households and communities, reduce their ability to sustain themselves and result in poorer socialization, less formal education and ultimately cultural, as well as material, impoverishment. Although the problem of HIV-related impoverishment might usefully be thought of as a livelihood problem, this framework will ultimately turn out to be limited. A livelihood approach will only provide an entry point to a problem that is much wider. This perspective has applications beyond HIV and will be relevant to consideration of the effects of other communicable diseases.

That the HIV epidemic impoverishes people, their households, communities and enterprises is by now widely accepted. What is not well understood is how it acts on different social and economic units, how these interact with each other, and how we can better understand these effects and processes. There has been surprisingly little work on this problem.

HIV leads to financial, resource and income impoverishment. Households become poorer as a result of the illness and death of members, and in many cases it is the income-earning adults who are lost. However, impoverishment is more than financial. Illness and death leads to an erosion of social capital and socially reproductive labour. In other words, we are bound to consider impoverishment as a characteristic of systems rather than solely of commonly identified social and economic units. The notion of social reproduction is of greatest importance. It is not the same as ‘social capital’. The term is used to refer to the effort that goes into the reproduction of social and economic infrastructure. To give one example, we may think of market systems. At the purely economic level, a market is a mechanism whereby goods and services are exchanged through a process of price setting. At the social level, this system consists of a wide variety of relationships, including, for example: physical infrastructures, beliefs about trust, rituals of bargaining and price setting, mechanisms for regulating weights and measures, means of resolving disputes, and repeated activities that ensure that all these things continue to exist. These are not solely matters of economic activity. They include the maintenance and development of institutions, the reinforcement of systems of belief and the continuation of physical infrastructure and channels of communication. The effort that maintains these is the work of social reproduction. Death and illness means that some of these activities will no longer be possible or will be done less effectively.

Poverty is also about more than income and economics. There are many types of poverty:

- service poverty, where people are unable to access, or are not provided with, services such as health and education;
• resource poverty, where although they have sufficient incomes, people are unable to access resources because they may be poor in terms of their rights, representation or governance.

For reasons of space, this chapter focuses on income and social capital. This is not to say that other forms of poverty are unimportant. HIV will affect them as well and these are areas where further research and discussion are necessary, not only in relation to HIV but also in relation to the impact of infectious diseases more generally.

The impact of HIV on poverty

The pathways of impact are illustrated in figure 2. The first and worst impact is at the level of individuals and households. In the longer term, there may be a macroeconomic impact (see chapter 7). The precise scale and magnitude of macro-impact will depend on the number and location of the micro-level impacts. Early attempts to identify and predict macro effects were seen as a way of justifying action. If it could be shown that HIV would cause national economic growth to slow then it would perhaps be easier to make the political case for policy intervention.

Figure 2. Pathways to economic impact

![Diagram showing pathways of economic impact](image)

Source: Desmond, Chris, HEARD, 27 August 2001 - Report I, Epidemiology & Literature, p. 35.

Macroeconomic impact

In the late 1980s and early 1990s, a number of studies looked at the macroeconomic impact of HIV and AIDS. These suggested that national economies would grow more slowly as a result of the impact of the disease (Over 1992; Cuddington 1993). But these studies were based on modelled impact rather than observation. There was little additional work in this area until 2000. Why the renewed interest? The answer is:
1. The scale and speed of the epidemic has been worse than expected.

2. Known demographic effects are now such that recognition of economic consequences is unavoidable.

3. There is evidence of impact at micro levels, making macro impacts credible.

4. The complexity of the disease’s impact and the scope of its consequences are better understood. For example, loss of key government workers means work is not done efficiently, investment is reduced, and economic growth slows.

5. The development consequences of the disease are becoming apparent, so there must be a macroeconomic impact.

World Bank economist Rene Bonnel estimates HIV reduced Africa’s economic growth by 0.8 per cent in the 1990s (Bonnel 2000). HIV and malaria combined resulted in a 1.2 percentage point decrease in per capita growth between 1990 and 1995.1 In two countries, Botswana and South Africa, there has been some rigorous national level analysis (Quattek 2000; Arndt and Lewis 2000; Bureau for Economic Research (BER) 2001; BIDPA 2000). The conclusions of these analyses are that HIV will cause the economies to grow more slowly. Household income and expenditure will decrease, as will government revenue and domestic savings. One of the South African studies suggests that the main reasons are the shift in government spending towards health, which increases the budget deficit, reduces total investment and slows productivity growth (Arndt and Lewis 2000).

In Botswana, a report on the macroeconomic impacts of HIV and AIDS (BIDPA 2000) (one of a number of studies on HIV impact) focused on the effect of HIV and AIDS on GDP growth and per capita incomes from 1996 to 2021. It predicted GDP growth would fall from 3.9 per cent a year without AIDS, to between 2.0 per cent and 3.1 per cent a year with AIDS. After 25 years the economy would be 24 per cent to 38 per cent smaller.

It is increasingly recognized that conventional economics misses the complexity and full significance of the epidemic (MacPherson et al. 2000; BER 2001). When the epidemic was in its early stages, projections based on scenarios computed ‘with AIDS’ and ‘without AIDS’ were reasonable. Such comparisons are no longer valid. ‘The impact of the disease cannot be treated as an “exogenous” influence that can be “tacked on” to models derived on the presumption that the work force is HIV-free. HIV/AIDS has become an “endogenous” influence on most African countries that has adversely affected their potential for growth and development. In some cases, such as Zambia, Zimbabwe, and the region covering the former Zaire, the spread of HIV/AIDS may have already undermined their ability to recover economically.’ (BER 2001) HIV has the potential to push economies into decline and then keep them there. ‘The reduction in savings and loss of efficiency associated with the spread of the disease is akin to “running Adam Smith in reverse”.’ (BER 2001)
Thus we have seen the significance of HIV impact at the macroeconomic level. There are, however, additional consequences that have rarely been considered in the literature. These include the strong possibility that governments will have fewer resources to spend on poverty alleviation and social services at the very point when demand for those services is most likely to increase. In Botswana, the increased demand for resources and the likely reduction in revenue have been calculated. The Government will have to spend between 7 per cent and 18 per cent more by 2010 because of HIV, assuming current levels of service are maintained. The greatest share of spending will go to health care, followed by poverty alleviation. Revenue in Botswana is predicted to fall by 9.6 per cent – and this is a relatively protected economy because of the country’s huge diamond deposits. By 2011, South African Government revenue is predicted to be 4.1 per cent lower than in the absence of HIV (Quattek 2000).

Finally, the consequences for those not directly affected by HIV will be considerable. They will have to bear the consequences of the general slowdown in economic activity, erosion of government revenue and capacity, and other associated effects of the epidemic.

**Poverty impact at the household level**

Household and community-level impacts are most serious when considered within the macroeconomic context sketched above. The BER in South Africa warned that ‘the macro results may conceal more substantial negative impacts at a more disaggregated level’ (BER 2001 p. 42). Despite this type of statement, there is a paucity of information on the impact of HIV on poverty or on policy to mitigate it. What there is is sparse and uncoordinated. Indeed, it may be said that economic modelling, despite its well-known flaws, at least provides a baseline for discussing the poverty implications of the disease. In contrast, existing household studies tell us very little and there have been very few attempts to model the impact of HIV on households (Bechu 1998, pp. 341–8). From the limited household studies, it can be concluded that the effect of illness and death on poverty in households depends on:

1. The number of cases the household experiences – this is where clustering becomes important.
2. The characteristics of deceased individuals: age, gender, income and cause of death.
3. The household’s composition and asset array
4. The community’s attitudes towards helping needy households and the general availability of resources – the level of life – in that community.
5. Broader resources available for assistance to households – from the state or community-based and non-governmental organizations (CBOs and NGOs).
The limits of household studies

Household studies have limitations. These are:

- Even in the worst-affected areas, adult illness and death is comparatively rare.
- Because HIV is sexually transmitted, it clusters in households. The average household in a community will not be affected in any given year. This can be illustrated with a simple example. In a village of 100 households with an average of three adults per household, in a region with 10 per cent HIV prevalence and a mature epidemic, we would expect to see three to five adult deaths per annum. It is likely that only one or two households will experience illness or death in any one year. However, impact will ‘accumulate’ in the community.
- Most of the studies deal with Africa.
- Most are of rural households. Why this is so is unclear. It may arise from a basic paradox: foreign researchers want to work in rural areas, which, they believe, represent the ‘real’ Africa, and prefer to avoid places that are squalid or dangerous like poor parts of large cities. But in Africa and South Asia nearly a third of the population lives in urban areas. (UNDP 2000, p. 226).
- As their titles indicate, in most cases they are economic studies.
- Most frame the problem as a household study and depend exclusively on survey methods, thus failing to capture the most seriously affected households, those that have disappeared before the survey.
- Policymakers, politicians and agencies often demand quantitative survey-based studies because they have the ring of a form of evidential ‘truth’ that coincides with the demands of funders’ referees, who are often academics. Such forms of ‘truth’, although valid, are partial and do not tell of the underlying misery.
- Single, or even multi-visit, surveys unsupported by ethnographic methods tend to underestimate impact and tell us little about processes of impoverishment.
- Commonly used survey methods fail to capture the dynamics of household and intra-household allocation and relations that underlie household decision-making (Chong 1999, Rugalema 1999).
- HIV may be seen as the major problem by the researcher – who has written and submitted a research proposal or is responding to a terms of reference or scope of work document. Communities and households may not have the same perception of its importance. This was illustrated by a Zambian study that looked at how children were valued in a situation of environmental and social change. The social change identified by the researchers in an area with 14.8 per cent HIV prevalence among antenatal clinic attenders was increased morbidity and
mortality due to the epidemic. They concluded ‘research methods used in the study villages found that there was almost no link made in people’s minds between HIV/AIDS and either the value of children or fertility. At present AIDS is not seen as a major problem by the majority of people, despite its recognition as a worrying disease’ (Barrett and Browne 2000, p. 22).

- Measurement of impact of HIV on poverty is difficult. The effect of illness ranges from not feeling very well to complete inability to function. It is difficult to unravel these subtleties with survey methods because: surveys of ‘households’ will not collect data on complex relations between clusters of households; and the ‘household’ may not be the appropriate unit of analysis for understanding poverty effects of HIV-related events.

- Finally, the epidemic and its impact are still evolving. The HIV epidemic may have run its course only in Uganda and Thailand. In all other countries, HIV prevalence continues to rise and the number of HIV illnesses and deaths will follow suit some years hence. Thus surveys are trying to measure and quantify something that is still to happen.

**Short-term poverty impact**

Often the first sign of infection is when the youngest child (infected in vitro) fails to thrive and dies. The mother is likely to have been infected by her partner. It is estimated that 60–80 per cent of African women infected with HIV have had only one partner but were infected because they were not in a position to negotiate safe sex or prevent their partners from having additional sexual contacts. The next death is often that of the father, followed by the mother.

The illness has two effects on household resources and income. No matter who is ill, they will need care, medicines, treatment and possibly a special diet. All this costs extra money. When the person dies, the funeral will be a further drain on resources. The second impact is felt if the person is an adult. Their illness and eventual death will deprive the household of labour. This may be income earning or unpaid labour on the farm or labour used in caring for the family.

**Understanding the time scale of impact**

The impact on households is long term. It begins with illness, as additional resources are required for care and household labour is reduced. Unlike with many (if not most) illnesses, the person affected will not recover, but periods of illness will increase in frequency, duration and severity, requiring more care and, if the person is a labour provider, it results in a greater household labour deficit. Usually there will be more than one case in the household. Thus the pattern of illness and impoverishment may be repeated.
If the household dissolves then dependants, usually children but sometimes the elderly, either have to fend for themselves or be taken in by other households. Where care is provided by others, this means that, in many instances, fewer resources will be available to their own members. Examples include grandmothers in South Africa making do with a pension of less than $100 per month and caring for one or two children. As the number of dependants increases, so resources are stretched thinner. The net effect is that there is less for everyone.

Income, consumption and expenditure patterns

What effect does HIV have on household expenditure and consumption patterns? An adult illness or death reduces household income. Less labour is available, not only because the affected individual cannot work but also because time is diverted to care of the sick. Illness increases expenditure on medical care, food, washing materials, etc.

There are limited studies of the effects of HIV on households and most focus on economic impacts of death rather than illness. These paint a bleak picture. The classic survey-based study was in the Kagera region of the United Republic of Tanzania in the late 1980s and early 1990s by the World Bank with Tanzanian co-investigators. With regard to adult death, the Kagera study (World Bank 1997) found households experiencing an adult death spent less during the person’s illness, but that a greater percentage of their expenditure was on medical care. They spent 33 per cent less on non-food items such as clothing, soap and batteries and their food purchases decreased. Income was diverted, but may also have been reduced as the number of hours worked was cut (World Bank 1997, p. 213).

In South Africa, the Bureau of Economic Research modelled the impact of the AIDS epidemic on final household consumption expenditure. This is shown below. These results suggest that total final household consumption expenditure is slightly higher in the AIDS scenario over the period 2002–2010. This is explained by increased consumer spending on health care products and services (non-durable goods and services spending), use of personal savings and positive employment effects associated with the government and companies’ efforts to combat the epidemic (BER 2001, p. 33).

<table>
<thead>
<tr>
<th>Year</th>
<th>Durables Total</th>
<th>Semi-durables</th>
<th>Non-durables</th>
<th>Services</th>
<th>FCE</th>
<th>Savings</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>-1.0</td>
<td>-0.7</td>
<td>0.3</td>
<td>1.5</td>
<td>0.5</td>
<td>-0.5</td>
</tr>
<tr>
<td>2005</td>
<td>-3.1</td>
<td>-2.4</td>
<td>-0.1</td>
<td>3.0</td>
<td>0.7</td>
<td>-0.8</td>
</tr>
<tr>
<td>2010</td>
<td>-5.7</td>
<td>-5.4</td>
<td>-1.6</td>
<td>6.3</td>
<td>0.8</td>
<td>-1.5</td>
</tr>
<tr>
<td>2015</td>
<td>-7.9</td>
<td>-9.8</td>
<td>-6.3</td>
<td>3.5</td>
<td>-2.8</td>
<td>-0.2</td>
</tr>
</tbody>
</table>
Evidence from both Kagera (World Bank 1997) and Côte d’Ivoire (Bechu in Ainsworth et al. 1998) indicates that households are resilient and there is a partial recovery in levels of consumption as time passes after the death. In other words, households ‘cope’. However, our experience, and that of others, has been that anecdotal evidence often shows they do not cope, or that ‘coping’ may turn out to be another way of saying ‘desperate poverty, social exclusion and marginalization’.

There is an unresolved problem: existing quantitative studies indicate effective coping, while anecdote makes us believe otherwise. And recent work from Zambia supports this view. A five-year retrospective study of 232 urban and 101 rural AIDS-affected families found that: ‘One of the striking features of the economic impact of AIDS in affected families in Zambia is the rapid transition from relative wealth to relative poverty.’ (Namposya-Serpell 2000, p. 1) This was particularly marked where a father died (70 per cent of the recorded urban deaths). Monthly disposable income of more than two thirds of the families in this study fell by more than 80 per cent.

Household surveys underestimate the degree of household dissolution and failure. Mutangadura’s (2000) study of 215 households in Manicaland, Zimbabwe examined how adult deaths may cause the dissolution of households. She found that about 40 per cent of the sample households had taken in orphans who had lost both parents. More strikingly, she states that: ‘65 per cent of households where the deceased adult female used to live before her death were reported to be no longer in existence in both the urban and rural sites.’ (Mutangadura 2000, p. 11) This lends weight to the supposition that often the worst impact is invisible because it is among those who are not counted.

Death is expensive. In Kagera households, medical expenditures were higher when AIDS was the cause of death. But, ‘strikingly for all groups except men with AIDS, medical expenses were overshadowed by funeral expenses. On average, households spent nearly 50 per cent more on funerals than they did for medical care… In Thailand… just as in Tanzania, the households spent much more on funerals than on medical care’ (World Bank 1997, p. 211). It should also be remembered that, while the state may make some contribution to health care and medical expenses, home care and funeral costs fall entirely on households.

One method by which households cope is by sale of assets. Table 2 summarizes data on how adult death is linked to households’ disposal of assets from Kagera, United Republic of Tanzania and Rakai, Uganda.
Table 2. Asset ownership in households with and without an adult death (% of total households)

<table>
<thead>
<tr>
<th>Asset</th>
<th>Rakai District, Uganda</th>
<th>Kagera District, United Republic of Tanzania</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Households w/o adult death</td>
<td>Households with adult death</td>
</tr>
<tr>
<td>Bicycle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>First visit</td>
<td>34</td>
<td>39</td>
</tr>
<tr>
<td>Last visit</td>
<td>41</td>
<td>35</td>
</tr>
<tr>
<td>Radio</td>
<td></td>
<td></td>
</tr>
<tr>
<td>First visit</td>
<td>30</td>
<td>40</td>
</tr>
<tr>
<td>Last visit</td>
<td>37</td>
<td>36</td>
</tr>
</tbody>
</table>


Around the city of Chiang Mai in northern Thailand, 41 per cent of households where there had been an adult death had subsequently sold land, 57 per cent reported some other form of what economists euphemistically describe as ‘dis-savings’, while 24 per cent borrowed money (World Bank 1997, p. 218). In Zimbabwe, 24 per cent of households said they had sold assets to cope with the death of an adult woman with ‘the main assets being sold being cattle, goats, furniture, clothes, televisions, poultry and wardrobes’ (Mutangadura 2000, p. 15).

For rural and poor urban households to survive, it is crucial that they do not dispose of productive assets that are necessary for recovery and reconstruction. The assets described in table 2 are mainly consumer goods; a household can sell a radio and survive. The question is what happens when productive assets – a plough, oxen or seed stock – are sold. The implications for the future of such households must be bleak: they can no longer maintain and reproduce themselves.

Whatever the case, two points should be noted. The first is that people who are driven to sell the clothes of the dead or their own clothes can hardly be said to be coping: these are the actions of the desperately impoverished. And, following from this, we have to be aware that the very notion of ‘coping’ is deeply ideological and may smack of the rich telling the poor how to manage their poverty (Rugalema 1999).

### Household reproduction, size and structure

What effect does the epidemic have on household reproduction, the household’s ability to sustain itself from day to day and to reproduce itself over time? The demographic impacts on households affect their ability to reproduce themselves at all. Households with adult female infections experience lower birth rates and higher infant and child mortality rates. In households where one or both parents have AIDS,
the likelihood is that fewer children will be born and a significant proportion of those who are born will die very young. Inevitably, this means that the personnel of the household are not reproduced and neither are the life-ways and traditions of that household.

That the structure of a household experiencing a death will change is axiomatic. It might be assumed that one unit – the deceased – would reduce its size. However, evidence from a number of studies suggests that in practice the change is hard to predict. In Kagera, most households experiencing a death added at least one member when a previously absent member or non-member joined. The average size of these households declined by less than one (from 6 to 5.7). In Rakai, Uganda, by contrast, mean household size fell from 6.4 to 4.7 (World Bank 1997, p. 215). People left the household, perhaps children were sent to stay with relatives or adults moved in search of employment. In Thailand, the decline was from 4.1 people per household to 3.1, the decrease being equivalent to the death of the one person (Janjaroen 1996). The significance of this has not been evaluated but it should draw to our attention the regional and national effects of large numbers of deaths in a community.

Deaths in individual households have implications for other households because of their interdependence. Rugalema (1999) shows how coping mechanisms become increasingly weakened as more households in a community are affected and communal support networks are less and less able to cope.

It has been argued by some that an entity called ‘the extended family’ will absorb the orphans and destitute created through AIDS-related mortality. This view has been heard from people ranging from senior policymakers in international agencies to politicians in Africa and Asia and people in local communities. The reasons for this are:

• the extended family is variable, it is dynamic and can become more or less extended depending on resource availability;

• ideological, it is something people want to believe because it validates their traditions;

• ideological, because belief in it relieves politicians of responsibility for thinking through the implications of the epidemic.

However, this view is now heard less as the full effects of the epidemic become apparent.

Affected households will try to adapt. One way in which they do this is by changing their composition. Three key points must be made:

1. Societies where extended households are the rule or where clusters of households operate together to pursue a common livelihood strategy may be more robust in the face of adult death.
2. Sending children to stay with relatives means the effect of the adult death will be felt beyond the sending family. Whoever takes care of the children can expect to expend resources.

3. Orphans need care, either in other families or through some form of public support. Increasingly they do not receive this support.

New forms of household are developing as a response to the impact of AIDS. Some of the more unique responses include elderly household heads with young children; grandparent-headed households; large households with unrelated fostered or orphaned children attached; child-headed households; cluster foster care – where a group of children is cared for formally or informally by neighbouring adult households. Unfortunately, where care is not available, children are increasingly itinerant, displaced or homeless, often in groups or gangs or found in subservient, exploited or abusive fostering relationships (Hunter 2000, p. 195).

The unmeasured impact on poverty

Economic studies of impact have understandably tended to focus on ‘economic’ variables. Economics studies what economics studies. But the impact of HIV on poverty goes beyond these relatively easily measured and familiar variables. In particular, it engages with what may be called relational goods, public goods and issues of social reproduction (Barnett, Whiteside and Desmond 2001). Social relations contribute to well-being. They may be:

- relational goods (Gui 2000);
- goods that have characteristics of being 'public' or 'common' (e.g. transport infrastructure).

It may not be possible to supply the former category through markets, depending on whether a relationship, which is the good, is provided through a market. For example, a foster parent provides care and support and a parent provides love as well. Can money buy love; how do you cost a cuddle? The latter is not supplied or is undersupplied by markets because individuals and corporations have little incentive to supply those goods. Relational goods can be final consumption goods (i.e. valued for themselves) and/or intermediate goods (e.g. certain social relations may facilitate cooperation and trust). Social relations can be a source of value in themselves (Sugden 2000, Bruni and Sugden 2000).

The effects of loss of such goods are apparent at the household and community levels. The study of households and their interaction has long been an area of research for sociologists and anthropologists. There is information on how households cope with shocks and respond to disease. However AIDS is new and different. AIDS-affected households have to cope with more than one death, because the disease
clusters. They also have to deal with a long and debilitating illness that is costly in its use of resources – both financial and time – and that ends in death. In addition, the epidemic has a wider effect, weakening the ability of the community to lend support.

An in-depth study of the impact of the disease in Bukoba district of the United Republic of Tanzania (Rugalema 1999) illustrates the stark impact on households. In the study community, 32 per cent of households were HIV afflicted – they had experienced direct illness or death of one or more of their family members in the last 10 years. A further 29 per cent were affected ‘in the sense that although they have not experienced direct death or illness of a household member from AIDS, they have experienced ripple effects… include[ing] fostering orphans, providing labour or cash to help care for the sick person, and providing for survivors in an afflicted household’ (Rugalema 1999, p. 73).

The worst impacts will be felt in households and clusters of households. It is here that costs of the disease have to be borne. It is here that mitigation interventions have to be located if they are to be cost-effective and sustainable. It is here that social reproduction occurs at its deepest level: in the stories told by parents and grandparents to their children, in the giving and receiving of affection, in the taking and relinquishing of responsibility. It is also here that the state and large multilateral agencies have most difficulty responding. The scale is too small and the variability in circumstance too great to be covered by large programmes. The great danger is that it is here – where it is most needed and where the very long-term costs are stacking up – that response to impact will be impossible because there is no way of dealing with small scale and large variability. This is a major policy challenge.

The intergenerational bargain

Another area where the loss of relational goods is significant is in the relations between the old and the young. The HIV epidemic has altered and will progressively alter the demographic structure of many societies. These demographic changes are indicative of long-term impoverishment, as relations of intergenerational support become eroded or impossible.

Under normal circumstances, parents care for their children and then in later years are supported by them. Some social scientists describe this as the ‘intergenerational bargain’ (Carmichael and Charles 1999; Collard 1999). In Greek tradition, this has been likened to a vine, where the young adults stand straight and firm as the new shoots climb up and the old ones make their way down to the earth. If you take out the middle support, the children cannot climb and the old collapse.

This is one of the core and most important bargains made and maintained between people. It is a basis on which social order is constructed: its destruction...
points to impoverishment far beyond the material. In most societies there is no social pension or welfare, and while people may accumulate assets during their productive years, these are often not, on their own, enough to provide for old age.

Care of the aged is a global issue. In all societies, people are living longer, or at least they were before the advent of AIDS. In wealthy societies, there is increasing concern about how to respond to ageing populations. Here, the problem is the potential burden of care and support that the young face in caring for the increasing number of elderly. In the poorer, HIV-affected countries, life expectancy may be falling but this overall figure disguises the fact that people who reach their 50s and 60s have a much better chance of living into their 70s and 80s. HIV impact is therefore being felt in a setting where ageing and care for the elderly were already issues of concern. It makes a bad situation worse.

The effect of HIV on the young needs to consider all who are HIV-affected. The classic definitions of an orphan by UNAIDS is ‘a child under 15 who has lost either both parents (double orphan) or the mother (maternal orphan), and it is from this definition that the UNAIDS global estimation is made’. This underestimates the ‘true’ number of orphans. In addition, the definition needs to be expanded to consider children who are affected prior to the death of parents and also children in households that take in affected children. Definitions are important and there is no final way of deciding who is or is not an orphan. It is a social role, and varies from place to place and culture to culture, and impoverishment goes beyond the mere fact of being orphaned.

Long-term impoverishment

The World Bank’s study in Kagera showed that even in ‘richer’ households (and we must not forget that these are all very poor communities), 29 per cent of non-orphaned children were stunted (had a very low height for their age) while 50 per cent of orphaned children were wasted. In poorer households, 39 per cent of non-orphaned children were stunted while 51 per cent of orphaned children were wasted (World Bank 1997, p. 224). These figures point to the effects on all children of growing up in a poor society.

Stunting has long-term effects. Foundations for future life are poorly built with poor physical condition, compromised immune systems and mental functioning. This will affect the ability of children to benefit from education and to function socially and economically later in their lives. It can cripple a society for a generation or more.

Orphans are less likely to have proper schooling. The death of a prime age adult in a household reduces a child’s school attendance (World Bank 1997, p. 225). Households may be less able to pay for schooling. An orphaned child may have
to take on household or income-earning work. Sick adults may have reduced expectations of the returns to investing in children’s education, as they do not expect to live long enough to recoup the investment. When children go to another household after their parents’ deaths, the obstacles become greater, as the new carers are likely to be less committed to them.

The standard of education that a child receives may be low. This is in part because of the under-resourcing of public education; it is also a result of the HIV epidemic. As increasing numbers of teachers die from AIDS, they may be difficult to replace, particularly in deprived, rural or otherwise remote communities. When teachers have an HIV-related illness, classes may remain untaught for extended periods, as replacements are difficult.

In Kagera, children from poor households had the lowest school enrolment rates, whether they were orphaned or not. But orphaned children inevitably had lower rates than non-orphaned children. Differentials are striking. The enrolment rate for non-orphaned children between the ages of 7 and 10 from better-off households was 44 per cent. But for orphaned children in the same age group and from poorer households, the rate dropped to 28 per cent (World Bank 1997, p. 228).

Girls carry a larger burden of domestic responsibility than do boys and are more likely to be kept out of school. As with much else about HIV and AIDS, impacts are interrelated: poor nutrition, poor care, and poor or little schooling affect orphans. Other children in the community are affected by general household impoverishment.

Caring for children has costs. Taking in orphans increases demands on household resources. In societies affected by HIV, many children live in households in which their own parents have fostered or are fostering orphans. In a study in Buganda, southern Uganda in 2000 (Monk 2000), 152 households were interviewed. A total of 342 non-orphaned children resided in these units. In addition, there were 383 orphans. In the majority of cases, there was no distinction between levels of care given to orphans or to the guardian’s own biological children. Therefore, all children in the household suffer the same economic and other deprivations resulting from spreading resources more thinly as a ‘coping’ response to the epidemic.

HIV disrupts social roles, rights and obligations. For the orphaned child there is often a premature entrance to burdens of adulthood, all without the rights and privileges – or the strengths – associated with adult status. Becoming an orphan of the epidemic is rarely a sudden switch in roles. It is slow and painful, and the slowness and pain have to do not only with loss of a parent but also with the long-term care which that parent’s failing health may require. Children who care for adults may experience a world gone seriously awry. A young girl of eight or nine may be used to caring for younger siblings; she is unprepared to care for her mother, father or both of them. As well as the physical difficulties, there are inevitably difficulties
of culture and sensibility. Coping with a parent who is weak and requires food cooked or water brought is one thing. Coping with a parent’s severe diarrhoea, declining mental function and mood changes is quite another. Children also become uncommonly familiar with death.

It is not only in relation to their own parents that children take on new and premature roles. When they become orphans, they go to their grandparents or to another relative. An aunt or uncle may also die of AIDS or a grandparent from old age. Double or even triple orphaning is not unknown. It is all too common for quite young children or early adolescents to be caring for aged and infirm grandparents.

These unmeasured consequences for the orphan generation are of great concern. We are talking about unsocialized, uneducated, and in many instances unloved, children struggling to adulthood. The cost to them as individuals remains unmeasured. The costs to the wider society are potentially enormous and already being felt and seen.

It has been speculated that the high levels of orphaning will lead to an increase in crime. This has been spelt out as follows for South Africa: ‘AIDS and age will be significant contributors to an increase in the rate of crime over the next 10 to 20 years. There will be a boom in South Africa’s orphan population during the next decade… Growing up without parents, and badly supervised by relatives and welfare organizations, this growing pool of orphans will be at greater than average risk to engage in criminal activity.’ (Schönteich 1999, p. 1) At worst, there may be increased political instability with orphans swelling the ranks of the child soldiers (Zack-Williams 2001).

Poverty and older people

Population ageing is now a global phenomenon and is set to accelerate over the coming decades. The standard definitions, population aged 65 years or over, do not reflect the nature of old age in most of sub-Saharan Africa and other poor regions of the world and in poor communities. Limited life expectancy, poverty, hard work, frequent illness and, in the case of women, childbearing all result in relatively early onset of ‘old age’.

In contrast to children who are orphaned or otherwise at risk, older people are less appealing to donors. There is prejudice against older people and rapid social change and ‘development’ often place them in positions of severe disadvantage. For example, the migration of young adults from rural to urban areas means that their adult children will not be around to look after them. The changed status from respected elder to burdensome old person is particularly likely when their children’s generation ceases to take traditional responsibilities seriously as they pursue new individualistic lifestyles. The AIDS epidemic magnifies all of these problems, and
older women face more difficulties than older men. Rural old women are among the populations most adversely affected. A measure of the degree to which the impact of HIV and AIDS on older people has been neglected is that we are aware of only one scientific study and indeed few other publications on this express theme.6

The main problem that confronts the elderly in a society affected by HIV is poverty. An inevitable second problem is grief. Grief and poverty go together for the old because the epidemic affects them through the death of one or more of their adult children. Older people are likely to be among the poorest in poor societies. Their failing powers make it more difficult for them to work on a farm or earn a living in some other way. They become increasingly dependent physically and financially in all societies and once again ‘the extended family’ and its strengths can turn out to be more myth than reality (Laslett 1965; Gubrium 1973; Foner 1984).

Poverty and frailty are made worse in two main respects by the loss of adult children. One is the loss of financial and other support that they could have expected and might have received. The other is the unexpected burden of orphaned grandchildren who come to live with them.

In contrast, a rich older person can buy his or her way out of the worst effects of the death of an adult child or children. Fieldwork in rural Uganda in 1989 identified an apparently prosperous elderly couple. In-depth interviews elicited the following story: The couple had worked hard and saved by investing in their children’s education. For many years they had enjoyed the fruits of their investment in remittances from their son, the headmaster, their daughter, the nursing sister, and their other sons, both government officials. Then one by one, and in quick succession, the children all died. The couple found themselves hosting 15 grandchildren from under two years of age to mid-teens. Their solution was for the old man, now in his eighties, to take a young woman of 26 as his second wife. This is one way of coping but it is restricted to the relatively rich. The reality for the majority of the elderly is quite different.

Old age: poverty exacerbated

A detailed 1998 study of older people in Buganda (Williams 1998) illustrates graphically the conditions that the elderly endure in a rural society in Africa. They have poor housing and are often unable to build anew or to repair what they have. Poor housing means poor security and loss of food and other valuable items to insects, animals and theft. Preparing and cooking food can present challenges. Within their homes, poor old people may not have sufficient bedding to stay warm at night. One of Williams’ respondents told him: “I sleep on a bark cloth on the ground and I cover myself with my dress. I’d sleep better if I had a blanket.” Another said: “The problem is that I don’t have the strength to carry pots from outside and I am
afraid I will fall over. I used to have it [the kitchen] outside, but it was hard to get in and out of the door at night, and once I fell over. So now I have it in here, but I still fall down sometimes. When I cook near my bed I can cook lying down and that is easier.” (Williams 1998, p. 138)

Old people living alone face considerable difficulties obtaining water for washing, cooking and drinking. Failing adequate water supply, the results for the elderly may include thirst and hunger because there is no water with which to cook or wash dirty clothes. Lack of personal hygiene can lead to intestinal worms, associated with poor sanitary conditions (Williams 1998, p. 143). Another constraint is fuel wood. Collecting wood is a very labour-intensive and demanding task and old people often find it hard to obtain enough. The result of this, combined with falling ability to produce food from the farm or purchase it, is an inadequate diet.

The elderly are dependent. Dependence requires support. Support is found in social life. Social life requires energy and inputs if it is to be maintained and reproduced. The elderly lack energy to make these investments. That is why children are important and why when they die and their work, remittances and other support cease, the circumstances of an old person can decline dramatically. What then happens when the grandchildren come to live with them?

Old age and orphans

Williams suggests that: ‘Old people are affected by the epidemic more through the fulfilment of their parental obligations than the loss of their children’s support.’ (Williams 1998, p. 230) First of all they care for their children who are sick. Then they bury them. Finally they care for their grandchildren.

In Uganda7 as long ago as the late 1980s, aged grandparents had increasingly assumed responsibilities for rearing orphans. Lack of energy to work in the fields meant the range of food available to them and their dependants became smaller and their nutritional status became worse. Many grandparents with orphans said they faced problems of discipline. Young people were to be found playing truant in the nearby town and were identified by members of the community as orphans coming from grandparent homes.

But sometimes it is the sheer numbers of orphans who come to rest in the grandparent’s household that overwhelm its capacity to offer material and emotional care.

Young trees make a strong forest (Kiganda proverb)8

It is estimated that by 2005 just over 30 per cent of Malawi’s children will be orphans because of AIDS and other reasons. By 2010 that will have risen to 35 per cent
(Hunter and Fall 1998, p. 7). The situation in Malawi is no worse than in any other country of East, South and Central Africa; indeed it may be better.

The breakdown of intergenerational dependency and support is not unique to an HIV epidemic. It has been commented on in many countries of Europe (Carmichael and Charles 1999). Provision can be made through the market or the state in rich countries. Poor countries cannot provide support nets for their people. There is little in the way of public provision. People cope by caring for themselves in households and in communities as best they can.

The HIV epidemic confronts us with a new situation. Societies remain poor and will be further impoverished by the epidemic itself. The growth of dependent populations and the disappearance of mature adults erode the possibilities of ‘coping’ at the local level and nationally. This is apparent all over Africa but also elsewhere, for example in Ukraine. Ukrainians have the oldest average age in Europe, and per capita one of the largest numbers of pensioners. Under the Soviet system, a pension was provided by the state. Money did not come from investments but from current revenue. The dramatic decline in government revenues since 1991 has been reflected in a decline in the real value of pensions as well as delays in paying them. Not only are the old poor and without any substantial social safety nets, but, because of the unfavourable dependency ratio, they are unlikely to have either family or state provision in their final years. Our calculations suggest that, as a result of the HIV epidemic, there will be an additional 30,000 totally unsupported old people in Ukraine within 10 years (Barnett and Whiteside 1997).

The evidence from Africa and from Ukraine shows that a serious situation exists in both places. Throughout Africa, the intergenerational bargain is becoming progressively harder to maintain. The outcome is awful for the people themselves; its long-term effects have to be imagined as one, and possibly two, generations of children grow up with inadequate care.

The policy response

“Our extended family system will cope with orphans”, people used to say in Africa in the early 1990s. In Uganda it was realized and accepted by the mid-1990s that ‘the extended family’ system was (a) various and variable, (b) often not coping. Institutional care is unacceptable to people in Uganda and in most other parts of Africa. It is necessary to find ways to care for orphans within family and household systems that have been increasingly stretched, using institutional care as a last resort. Institutional care has a bad name in some places where ‘orphan farming’ has developed as an income-generating activity (Barnett and Blaikie 1992).

An assessment of the cost of orphan care in South Africa looked at six different approaches. The costs are summarized in table 3.
There is a wide range of care options, from the less costly informal to the more costly formal care models. Although community-based care and home-based care and support appear to be the most cost-efficient ways of caring for orphans, these models are not always appropriate or feasible. Appropriate resource allocation – a political and practical issue – is a major limitation to be addressed if the basic needs of the children are to be effectively met by informal family-orientated care models. In addition, the appropriateness of the less formalized care options in caring for children who may be sick or have suffered abuse needs to be considered.

It is difficult to know how to support households with children orphaned by AIDS. Targeting them is neither practical nor desirable and is potentially stigmatizing. It could also mean that other orphans and their carers – with the same needs

<table>
<thead>
<tr>
<th>Care model</th>
<th>Cost (minimum standard)</th>
<th>Increase</th>
<th>Reason for increase</th>
</tr>
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<tbody>
<tr>
<td>Community-based support structures</td>
<td>276</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Home-based care and support</td>
<td>306</td>
<td>+301</td>
<td>- Process for identification&lt;br&gt;- Process for placement and grant access</td>
</tr>
<tr>
<td>Informal fostering/non-statutory foster care</td>
<td>325</td>
<td>+19</td>
<td>- Higher degree of supervision&lt;br&gt;- Smaller scale</td>
</tr>
<tr>
<td>Statutory adoption and foster care</td>
<td>410</td>
<td>+85</td>
<td>- Security of accommodation&lt;br&gt;- Quality of accommodation&lt;br&gt;- More administration</td>
</tr>
<tr>
<td>Unregistered residential care</td>
<td>956</td>
<td>+546</td>
<td>- High staff to child ratio&lt;br&gt;- Provision of emergency care&lt;br&gt;- Care of sick children</td>
</tr>
<tr>
<td>Statutory residential care (caring mainly for HIV-positive children)</td>
<td>2590</td>
<td>+1634</td>
<td>- Very high staff to child ratio&lt;br&gt;- Care only for sick children&lt;br&gt;- Meet statutory requirements for a children’s home&lt;br&gt;- High overheads&lt;br&gt;- On-site medical care&lt;br&gt;- On-site pre-school education</td>
</tr>
</tbody>
</table>
– would be excluded from benefits. The majority of orphans are in poor countries where even the better-off households are poor by the standards of rich countries. The problem is how to support all orphans and other vulnerable children more effectively in such contexts.

Botswana has the highest levels of infection of any country. It has a major orphan problem. Current discussions concern whether state intervention or institutional care are appropriate. As in Uganda 10 years ago, so in Botswana today. People say that fostering and institutional care are not part of the tradition, that the extended family will cope (Jacques 1998, quoted in Rajaraman 2001). But ‘the Rapid Assessment on the Situation of Orphans in Botswana tells a different story… of orphan suicides, destitute children eking their living out of garbage dumpsites, and a growing number of child-headed households. In a context of intense social and economic pressures, orphans are increasingly reported to be mistreated and abused by caregivers; deprived of their inheritances by opportunistic relatives and neighbours; forced to drop out of school to perform domestic labour or bring home wages; pressured into entering commercial sex work and vulnerable to sexual abuse.’ (Rajaraman 2001)

Although the Government offers some additional support for orphans, carers are sometimes reluctant to accept this assistance, particularly if acceptance may identify the dead parent as having died of AIDS. Or it may suggest that the family cannot cope, another stigma. Given the possibilities of abuse, neglect and poverty, Rajaraman suggests that the Government has an obligation to intervene, in order to protect the human rights of the children involved. This does not imply overriding traditional systems of caring for orphans; it will, however, mean developing institutions to monitor, support and supplement them. But despite considerable rhetoric and funding, the Government of Botswana does not yet appear to have developed a structure of care for orphans. NGOs, and particularly the faith-based organizations, are bearing the heaviest load. The Government has not yet introduced an effective system either for registering orphans or for ensuring that different ministries’ activities are coordinated to provide effective support. This is the situation in one of Africa’s wealthiest countries; it is far worse in the poorer countries of the continent.

As the epidemic’s range increases, these problems will appear elsewhere. In Calcutta, India, there have been reports of numerous children orphaned by AIDS for some years, while in Ukraine, the predicted number of orphans in the next five years may well overwhelm existing institutional provision (Barnett, Whiteside et al. 2000). The Ukrainian case is of particular concern as the situation there is replicated in all of the former Soviet Union – implying a vast orphan population from the Polish border to Vladivostok. A visit to a Ukrainian orphanage in 2001 made the implications of this painfully clear. Children who have spent their childhood in an institutional regime that is simultaneously underfunded and based on the Soviet tradition cannot make a satisfactory transition to the world outside at age 16. This
is particularly so when the former Soviet support services of health care, employment and housing have disappeared. The deputy director of the orphanage was close to tears when describing the trauma for staff and orphans of pushing the children out of the institution when they reach 16. In economic and social terms, in the ‘transitional economies’ of the former Soviet Union, the potential costs of ‘the orphan problem’, which existed before HIV but which will be exacerbated by it, is very large indeed. There are the immediate problems of institutional care, the costs of assisting the transition from care to adult life (a transition that will fail in many, if not most, cases), and finally the costs as these neglected people make their way through their societies, in most cases to a premature death.

**Current responses to HIV-related impoverishment**

There have been very few explicit responses to the social and economic impact of HIV. Most effort and money has gone into prevention. While this was a sensible response, the balance between prevention and impact mitigation responses has been wrong – particularly when it has been clear for at least a decade that there would be long-term social and economic impacts. Here we review what is known about the possibilities, limitations and prospects for responses in general. We then go on to make some concluding and inevitably brief observations about poverty-related responses to HIV.

The first thing to say is that most responses to poverty-related impacts of HIV have been at the local and community level. There are few records of poverty-related responses at the regional, national, and most certainly not at the international, levels. From the earliest days of the epidemic, the tendency has been to move with the dominant neo-liberal ideology and to phrase response in terms of ‘coping’. This has been inadequate because – as noted above – the concept itself has severe limitations.

**Current responses and the myth of coping**

Like sustainability, the idea and language of ‘coping’ has to be questioned in relation to HIV and its impacts. Yes, people ‘cope’; the alternative – not coping – means households dissolving or people dying. But it is odd, and indeed offensive, for the wealthy to suggest the poor should ‘cope’ and the rich will show them how to do it. The idea of ‘coping’ originates from the unwillingness of the rich to do anything more than apply sticking plaster to the wounds of global inequality when what has been required for a very long time is expensive surgery. This surgery requires major transplantation and reorganization of resources.

Rugalema (1999) argues that coping is often a myth because:

1. Many households affected by HIV do not cope. On the contrary, they break up and their members, orphans, widows and the elderly, join other households.
2. It is not households that cope – rather it is individuals within them who manage to survive.

3. There may be precious little in the way of ‘strategies’ about how people manage crises. Rather, the decisions made by household members may merely reflect efforts to survive in the very short term.

4. Short-term solutions to crises – sale of household assets, withdrawal of young girls from school to help with domestic and farm work – have long-term effects and costs. These may include lower or no educational achievement, poor diet with associated stunting or wasting, lack of care and poor socialization.

5. The impact of a large-scale event such as an HIV epidemic has effects on wider social, economic and even environmental systems. For example, in a community or region that is hard hit, there are changes and costs at the levels of the farming system, social infrastructure and the maintenance of physical infrastructure. These all point to general impoverishment in many dimensions.

6. The effects of ‘coping’ are shouldered unequally between poorer and better-off households, men and women, generations, and different social groups and geographical regions.

Why use the term ‘coping’? It originates in literature about individuals and how they cope with stress (McCubbin 1979; McCubbin et al. 1980). It has been used to discuss famines (Watts 1983; Corbett 1988; De Waal 1989; Devereux 1993). Other roots lie in ideas from social work and childcare. Here the notion of ‘good enough care’ (Winnicott 1965) emerged in the 1960s. It was an attempt to sensitize social workers to the idea that, while their clients’ standards of care might appear inadequate by their own social and cultural standards, the clients’ was ‘good enough’ as long as everyone was ‘coping’.

In relation to HIV, the story of coping mechanisms is really a part of the wider story of structural adjustment policies – before they began to be offered ‘with a human face’ (Mehrotra and Jolly 1997). Rugalema hits the nail on the head when he says that the concept of coping strategies is rooted in the neo-liberal worldview of the 1970s and 1980s. Non-intervention by governments and freedom or autonomy of economic agents to participate in the market were fundamental points of departure. As this worldview dominated that period, not least due to the influence of Reaganomics in the US and Thatcherism in the UK, so the concept of coping strategies gained credence (Rugalema 1999, p. 5).

It is well known that human societies have developed and continue to develop ‘coping mechanisms’ and risk-sharing mechanisms for dealing with adversity; it is also well known and evident that there are severe limits to those mechanisms, that they do break down. The notion of a ‘coping mechanism’ can surely only be
maintained when a society or community remains able to meet its needs at some culturally acceptable level – hence the importance of the distinction between ‘famine’ and ‘famine that kills’ (De Waal 1989) among dryland people in Darfur, who distinguish between ‘mere’ famine and the other type. Coping becomes impossible. It is for these reasons that we are sceptical about and critical of the all too frequent use of the term ‘coping mechanism’, derived as it is from disaster theory and in particular from famine theory (Rugalema 1999). The notion has limitations when applied to famines and implies a rational response following logical processes of retreat in the face of a shock. It is a notion that fits comfortably with neo-liberal ideologies that assume and often implicitly make moral judgements about the desirability of a particular calculating stance towards the world on the part of individuals and households. *The Little House on the Prairie* comes rapidly to mind, but the point here is that, for each little household that made it into literature, there were others that perished. This becomes downright cynical when very poor people are told that they are ‘coping’ and their strategies are studied and reported to little purpose other than to provide assurances to major lenders such as the World Bank that their policies are in some sense working.

We have underlined the social roots of the HIV epidemic and the social and cultural filters through which its impacts manifest themselves. Coping is about dealing with risk. Risk is not equally distributed. It is constructed for individuals and socioeconomic groups through complex processes of economic, social and cultural relations. The constant struggles to survive that characterize the livelihoods of so many do not leave room for coping in the extraordinary circumstances in which many poor people live. That is what they do every day of every year. That is the nature of poverty. And when the big crisis hits them they do not cope. Thus, to talk of such poor people ‘coping’ is to cross the line between technical appreciation of what is possible and barely disguised cynicism and clear acceptance that different groups of human beings can only be offered second, third or worst best options. It is to accept the unjust structures of distribution in the world. A term such as ‘coping’ may be a way of escaping from the challenge of confronting how people’s capabilities are stunted, their entitlements blocked and their abilities to function as full human beings with choices and self-definitions frustrated.

**Transfer interventions**

We have already noted that little is known about responses to HIV-induced poverty. This is for three reasons:

1. There have been no large-scale interventions.

2. Most interventions have been small-scale and community-based (often components of ‘coping’) initiated by CNGOs, NGOs or in a few cases (such as Action
Aid) by large NGOs – major international actors such as Oxfam, World Vision, Save the Children or Care).

3. Above all because the interventions have not been documented.

Most interventions have been small-scale. It is only in the last year or so that large-scale programmes are coming into existence. This is evident most of all in the World Bank’s Multi-Country AIDS Programme for Africa (MAP), which had approved nine projects funded by the end of 2001 and a further 16 in the pipeline. Despite the efforts of the ACT Africa (AIDS Campaign Team for Africa) group in the World Bank, who have been responsible for pushing this initiative, what is most significant about it is that so little is being done so late in the epidemic – particularly given the lavishly funded Kagera household study that was done almost a decade previously!

Current (November 2001) World Bank publications about the MAP project (World Bank, ACT Africa, Multi-Country HIV/AIDS Programme for Africa, November 2001, CD-ROM) provide information about nine programmes11 funded by the initiative. While these programmes are broad-ranging and indicate that impact issues do at least figure in addition to prevention measures, none of the programmes seems to have poverty-related transfers as a focus for their activities. It is not that transfers are excluded – they could be included in a large number of community-based activities that might be funded. Rather, it is that transfers are an option rather than a recognized component of the strategies that have been jointly developed for each country.

This is an interesting situation. The Bank is responding to pressure and opinion. Its activities in this sphere are in fact quite limited and these soft loans are not large. Few are much bigger than a few tens of millions of dollars, and even Nigeria’s is under $100m over 5 years repayable over 35 years. The Bank is endeavouring to respond to local need and to make the process participatory (as between government and funder) and yet, despite the best efforts of the ACT Africa team, programmes remain not only prescriptive but prescriptive to a degree that appears to reduce the possibilities for transfer programmes. This is clearly shown in the following outline of what the overall programmes are intended to cover:

‘The proposed project will support key components, including:

**Prevention**, including information, education, and communication (IEC) for specific target groups, condom promotion, voluntary counselling and testing for vulnerable groups of the population; participatory approaches to behaviour change;

**Care and treatment**, including the treatment of STIs and opportunistic infections such as TB; strengthening the availability of and access to essential drugs,
training of health workers, clinical management of HIV-related conditions, and support to home and community-based care and support activities; ensuring a safe blood supply through improved screening and blood transfusion;

Research and surveillance, including baseline surveys of epidemiology, knowledge and behaviour, improved HIV sentinel surveillance to monitor the epidemic, and analysis for the design and implementation of cost-effective interventions;

Capacity building for programme coordination, resource management, and implementation at all levels; and

The establishment of sound monitoring and evaluation systems to enable programme implementing agencies to monitor performance indicators for each component of their programs.

(World Bank, MAP, 2001, file MAP Operation, p. 4)

This initiative is important but it raises some crucial questions about poverty-related interventions. A key idea in the World Bank’s approach is ‘scaling up’ of local-level initiatives. For some time this has been pushed hard by Hans Binswanger (Binswanger 1999). The approach has some difficulties. On the one hand, large lenders like the Bank have to be seen to disburse large amounts of money; on the other, scale may not always be easily combined with the specificities of local circumstances and with requirements for national and community ownership of programmes and projects. So, the need to respond on a scale in keeping with the perceived urgency of the situation may not necessarily result in projects that really meet local needs.

Interventions have mainly been small-scale and under the auspices of NGOs of one kind or another. These have not been described in any detail and have rarely been evaluated. Here we summarize a number of these in case study format.

i) The Firelight Foundation (www.firelightfoundation.org): This US-based organization operates on a very small scale and concerns itself with children affected by HIV and AIDS. It gives one-year grants of $500 to $20,000 to grassroots, community-based projects directly supporting the fundamental needs and rights of children orphaned or affected by AIDS in sub-Saharan Africa. These projects have aimed to train children, pay school fees, and in some cases provide food and medicine. The organization has been active in Kenya, Rwanda, South Africa, United Republic of Tanzania, Zambia and Zimbabwe. Its activities up to and including the year 2001 are summarized in table 4. Projects in which some type of transfer can be said to take place are italicized.
Table 4. HIV programme of the Firelight Foundation

<table>
<thead>
<tr>
<th>Country</th>
<th>Programme Name</th>
<th>US$</th>
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<tbody>
<tr>
<td>Kenya</td>
<td><strong>Rural Education and Economic Enhancement (REEP), Butula District</strong></td>
<td>30,000</td>
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<td></td>
<td>The grant will provide guardians and foster parents of orphans: training in</td>
<td></td>
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<tr>
<td></td>
<td>counselling, project management, and savings programmes **as well as offer food</td>
<td></td>
</tr>
<tr>
<td></td>
<td>aid. They will also train orphans in vocational skills, project management and</td>
<td></td>
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<tr>
<td></td>
<td>reproductive health.</td>
<td></td>
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<tr>
<td></td>
<td><strong>Teenage Mothers and Children Family Health Care (TEMAC), Eldoret</strong></td>
<td>2,500</td>
</tr>
<tr>
<td></td>
<td>The grant provides <strong>food and medicine</strong> for the children.</td>
<td></td>
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<td></td>
<td><strong>Catholic Diocese of Kitui-Orphan Support Programme, Kitui</strong></td>
<td>5,000</td>
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<tr>
<td></td>
<td>The grant will assist the programme to train social workers and orphans,</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>purchase drugs</strong> and provide other social programmes.</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>WiRED, Advanced Technical Assistance to Orphans, Mombasa</strong></td>
<td>7,350</td>
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<tr>
<td></td>
<td>The grant will train six AIDS orphans in a pilot programme of computer learning</td>
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<tr>
<td></td>
<td>at a conference in Mombasa.</td>
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<td><strong>Community Resource Mobilization Initiative Group (COREMI), Raibai</strong></td>
<td>12,000</td>
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<td>Funding will offer <strong>vocational training for 20 orphans</strong>, and counselling and</td>
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<td>training for 45 community AIDS educators.</td>
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<td><strong>Kibera Community Self Help Programme (KICOSHEP), Nairobi</strong></td>
<td>21,000</td>
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<td>The grant provides for <strong>orphan support</strong> through KICOSHEP’s various programmes.</td>
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participating in a Firelight funded pen-pal programme with Anzar High School in California.

**Botshabelo Babies Home, Midrand**
http://www.botshabelo.co.za
The grant will pay for half of the yearly salary of a social worker, the cost of two caregivers and some operating costs.

**South Coast Hospice's Memory Book Project, Port Shepstone**
The funds will provide 200 rural children about to be orphaned with a Memory Box. The box contains a letter from their mother giving her hopes and dreams for them, along with photos and other small mementos.

**United Republic of Tanzania**

**Activities Related to AIDS Orphans, Musoma**
The grant will make available services to 140 orphans and vulnerable children including: educational, counselling and support services, material aid to attend school and peer education programmes to improve community outreach.

**Education for AIDS Orphans & Peer Education and Service, Musoma**

**Youth Alive Programme, Musoma**
The grant covers school fees and related expenses for 30 orphans. The Youth Alive Programme grant covers the purchase of six bicycles, the coordinator’s salary and an emergency fund for people with AIDS. The Youth Alive Programme trains youth outreach volunteers to visit rural people ill with HIV.

**School Fees & AIDS Out-Reach, Mwanza**
Funding will assist more children to attend primary school through the provision of fees and food assistance. In addition, the Youth Alive group will be able to continue programmes, plays, and training to teach other young people about the dangers of HIV.

**Zambia**

**Anglican Street Children Project, Lusaka**
The grant will enable the Project to provide counselling, school needs (books, uniforms, pens, and shoes) and other basic necessities of the children as well as providing outreach to their parents and/or guardians.

**Fountain of Hope Shelter for Street Children, Lusaka**
The grant will enable 40 mothers to receive business skills training and seed money for small businesses. Helping mothers is one of the most sustainable ways to help orphaned children. The grant will also pay for 32 children to attend one year of secondary school.

**Zimbabwe**

**Salvation Army Masiye Camp, Bulawayo**
http://www.masiye.com
With the grant, Masiye Camp is establishing an emergency fund, which will assist over 200 of the most needy orphans.
Child Protection Society, Harare
The grant will fund three desktop computers, one printer and supporting software as well as vehicle costs.

Girl-Child Network-Safe House & Training, various locations
The grant will enable the Girl-Child Network to establish its third safe house for girls escaping sexual abuse in the village of Rusape. It will also cover the cost of a counselling workshop dealing with sexual abuse for club coordinators.

Island Hospice, Children’s Support Programme, Harare
The grant will pay for training and support to institutions and communities involved in the care of terminally ill children and orphans. The training includes grief and bereavement counselling and therapy for caregivers of children and support sessions for bereaved children.

Discretionary Grants

Girl Child Network, Zimbabwe
To support the cross-training of two women from Fountain of Hope in Lusaka, Zambia to provide services for the vulnerable girl-child.

Girl Child Network, Zimbabwe
For miscellaneous educational expenses.

Children Affected by AIDS Foundation, Los Angeles, California, USA
To further their work with children.

AIDS Outreach Programme, United Republic of Tanzania
Paid shipping costs of donated children’s books for distribution in local schools.

Paediatric AIDS Foundation, Santa Monica, California, USA
Funding for Call to Action, a project to reduce the rate of mother-to-infant transmission through: community education, health care worker training, HIV counselling and testing, and the provision of antiretrovirals to prevent MTCT.

There is no evidence that this programme and its associated projects have been externally evaluated.

ii) CINDI – Children in Distress (www.togan.co.za/cindi/): An informal South African consortium of more than 30 government and non-government agencies, this organization collaborates around the issues of children affected or orphaned by AIDS. It is supported by the Department of Welfare and Population, KwaZulu-Natal and the Nelson Mandela Children’s Fund. The organization does not set out to make transfers but it does provide some school scholarships for children in South Africa, as well as providing access to and dispensing some medicines. It also gives some free toiletries and disinfectants. Its activities are small-scale and community oriented. There is no evidence that the programme and associated projects have been externally evaluated.

iii) AIDS Orphans Education Trust (www.orphanseducation.org): This is a Ugandan NGO. Its aim is to provide an education, either formal and/or vocational, to
poor children whose parents have died of AIDS. It certainly makes a variety of transfers, including support for school fees, school materials and clothes. The AOET also provides support to widows in the form of blankets, food and laundry soap, as well as clothes for families of sick people or families caring for orphans. There is no evidence that the programme and associated projects have been externally evaluated.

iv) **International Fund for Agricultural Development** (www.ifad.org): This specialized agency of the UN provides microcredit to rural communities, especially in Uganda. IFAD works through a partnership with the Belgian Survival Fund and UWESO (Uganda Women’s Effort to Save Orphans). The associated UWESO Development Project has enabled 2,000 young children to attend primary school and has provided vocational training for older children. There is no evidence that the programme and associated projects have been externally evaluated.

v) **USAID’s Community-Based Options for Protection and Empowerment (COPE) project in Malawi**: This project is interesting because its aims are not to make transfers but rather to facilitate communities’ potential to develop income-generating activities and to make internal transfers – for example through the creation of food banks. The project was evaluated in January 1999 (Lloyd Feinberg, Namposya Serpell, John Williamson Review of the COPE II and OVC Programs in Malawi, January 8–24, 1999, Displaced Children and Orphans Fund and War Victims Fund Contract (HRN-C-00-98-00037-00), for USAID). An important question arising from this type of project is whether, in many cases, where the epidemic and its impacts are already very well advanced, such an approach is more in keeping with the ideological needs of the ultimate funder rather than meeting the requirements of the communities and households affected by the epidemic. Once again, Rugalema’s comments about ‘coping’ must come to mind.

vi) **Association François-Xavier Bagnoud (FXB) Micro-Grant and Education Programme for Orphans**: The FXB programme – among the earliest to respond to the HIV epidemic – helps families who are caring for orphans by providing micro-grants for income-generating purposes, paying for the primary education of one orphan per household, and educating people in hygiene, basic health care, and the rights of widows and children. It operates the programme in three subcounties around Luweero, a town 70 miles north of Kampala, Uganda, where many children have been orphaned by AIDS or civil war.

Each autumn, the 90 neediest families in each subcounty are offered a one-time $100 grant for the income-generating activity of their choice. Because of the lush grazing land, about 80 per cent of the families elect to rear animals, with the remainder primarily engaged in coffee or banana cultivation. Rather than providing their clients with the $100 in cash, FXB social workers purchase the agreed-upon goods for them. FXB hires a veterinarian to select the healthiest animals and, since they are buying 30 to 40 cattle at a time, FXB can negotiate the best deal.
An evaluation survey in 1999 found that over 80 per cent of the FXB micro-grants given since 1992 have met the objective of increasing the income of the families taking care of orphans.

FXB pays for the primary education of 3,060 orphans per year. The school fees are not paid in cash, but the PTAs determine what is most needed at the school (e.g. a new classroom, desks or books) and FXB pays the labourers for building the classroom or provides the desks or books directly to the school. In addition, FXB holds a competition among each year’s Primary 7 (7th grade) class, and the top six students are given scholarships to secondary school. The rest are eligible for vocational training.

FXB relies upon a committee of volunteers to run its programme. Each local committee area of guardians elects one spokesperson to represent them on the 50–60-person steering committee. The steering committees recommend the neediest families for the micro-grants, keep an eye on the orphans, monitor how the income-generating activities are working, coordinate with the schools, and provide regular feedback to the social worker running the FXB programme in each subcounty.

This approach to making transfers ensures that they are under community control and direction and works on a small scale. It is an approach that once more throws into sharp relief the problems of ‘scaling up’ as it deals in microlevel interventions and requires close attention to the role of the local steering committee.

Conclusion

We have emphasized that the relation between poverty and HIV and HIV and poverty is bi-directional. There is much conceptual confusion about the nature of the relationship, perhaps pre-eminently because so little rigorous research has been done, but also because of the ideological emphasis on ‘coping’ that informed much thinking about, and response to, the social and economic impact of the epidemic during the 1990s. Another factor was the general reluctance among academics and policymakers to take the issue of broad epidemic impact seriously. All too often they demanded ‘scientific evidence’ of impact, research that was rarely funded but which has now been provided by the unavoidable results of 20 years of impact on poor communities across the world, but disproportionately in Africa.

In the early 1990s, a very few NGOs (ActionAid, SCF UK and FXB among them) began to do something about the impact of the epidemic on poverty. By the late 1990s, more agencies took the issue on board – but few major multilateral or bilateral donors among them. It has been the NGOs that have made the running in providing transfer-based interventions. Their activities have been small-scale, variable in goals and intentions and usually unevaluated.
In summary, little has been done to respond to the impact of HIV and AIDS on poverty, we know little about it and have no idea whether these responses can or ought to be ‘scaled up’ or how to do that.

References and Bibliography


**Notes**

1 Recent work by the Liverpool School of Tropical Medicine suggests that the interactions between malaria and HIV may be marked. The rates of malaria fever rose sharply with falling CD4 cell counts. The data suggest that with worsening immunosuppression caused by HIV, protective immune responses to malaria in adults are progressively lost (Gilks, personal communication 2000).

2 According to the 2000 United Nations Human Development Report, 32.7 per cent of the populations of both sub-Saharan Africa and South Asia are urban.

3 The study was a four-round panel survey between 1990 and 1994. The survey looked at the impact of adult mortality and a total of 913 households were interviewed at least once, with 759 households completing all four waves. The study was funded by USAID, Danida and the World Bank Research Committee. The findings have unfortunately neither been fully analysed nor published, although some have been presented in various fora including international conferences. The most accessible account can be found in World Bank 1997. Some further findings were discussed in Lundberg and Over 2000.

4 AIDS-affected was defined as a family in which one or both parents and/or major breadwinner died due to AIDS in the five-year period from January 1991 to December 1995.

5 In many countries, fees are only part of the costs of attending school. There are book fees, building fees, PTAs, uniforms and, of course, the opportunity costs of time and labour foregone.

6 We arrive at this conclusion through a careful literature search, which turned up fewer than 10 articles, theses or books. Only Williams (1998) presents extensive and detailed data.

7 This section is based on fieldwork by Barnett and Blaikie in the late 1980s. It describes a situation that has not altered very much if at all and which is now more widespread in Africa and elsewhere than when these notes were first made.

8 Williams 1998, p. 216.


10 Personal communication from Veena Lakhumalani.

Chapter 9
Mitigating the Impact of HIV and AIDS on Education Supply, Demand and Quality
Carol Coombe

Introduction

This chapter focuses on the relationship between HIV and education in countries with different levels of HIV prevalence. While HIV affects all education sectors, the chapter concentrates on issues in schools, with some attention to teacher training colleges. It surveys experience from sub-Saharan Africa and Asia and the Pacific, and the lessons learned from high- and low-prevalence countries in those regions.

It also analyses the current and anticipated impact of HIV on education in order to clarify probable changes in demand for and supply of education services. Education’s responses to HIV, principally in high-prevalence countries, are discussed, with suggestions for ‘best practices’ at local, national and international levels in terms of cost, coverage and efficiency.

Definitions and assumptions

This chapter is based on several assumptions. The first is that increasing numbers of countries, especially in sub-Saharan Africa and the Caribbean, are facing one of the great crises of human history. The second is that other countries in Eastern Europe and the Asia and Pacific regions will confront similar challenges as the pandemic spreads (MAP 2001). Third, despite the difference in the nature of HIV and AIDS pandemics in the Americas and Europe, Africa, and Asia and the Pacific, it should be possible to extrapolate common ideas about what does and does not work in the response to AIDS.

As the pandemic snowballs, health-driven national strategies are being replaced by multisectoral strategies in which ministries of education take responsibility for identifying and driving education’s response, as in Botswana, Namibia, Rwanda and South Africa.
The role of the education sector in responding to AIDS: AIDS is raising four main questions for the education sector for which answers are only starting to emerge:

i) What is the role of the education sector in preventing the spread of HIV among young people?

ii) How can the sector ensure that all young people, especially orphans and other vulnerable children, achieve their full potential?

iii) How can the sector, which is the biggest employer in most countries, protect the viability of the education service, and therefore the quality of education provision?

iv) How can the education sector continue to improve access and the quality of education services in the face of HIV?

General agreement has emerged over the past three years (USAID 2001; Coombe and Kelly 2001; Inter-Agency Working Group 2001) that there are three principal areas of concern for sector partners:

i) Prevention: helping prevent the spread of HIV;

ii) Social support: working with others to provide a modicum of care and support for learners and educators affected by HIV; and

iii) Protection: protecting the education sector’s capacity to provide adequate levels of quality education – by stabilizing the sector and responding to new learning needs (Coombe and Kelly 2001; Inter-Agency Working Group 2001).

In addition, an effective response will require capacity in the sector to manage this crisis (Coombe and Kelly 2001).

The impact of HIV and AIDS on education

In countries with the highest prevalence, the impact of HIV on the education sector is apparent in the areas of both supply and demand as well as the overall quality, management and capacity to respond to new and complex demands (Inter-Agency Working Group 2001). The relationship between the HIV pandemic and education provision can only properly be understood within the context of the lives of people – children and adolescents and their families, teachers and principals, education officials and college lecturers – who are coping in the first instance with the impossible demands the pandemic makes on them as individuals. The impact on households directly influences the choices that learners and educators make (LoveLife 2000; Desmond in University of Natal, Health Economics and AIDS Research Division 2001).

Contextual factors affecting supply and demand

Socioeconomic conditions: Many at-risk learners come from the context of
socio-economic deprivation, complicated by and further complicating HIV infection, whether they live in North America, Europe, Africa, Latin America, the Caribbean or Asia–Pacific. AIDS is not a disease of the poor, but the poor are at higher risk of HIV infection, the poor are more vulnerable to HIV infection, and the disease makes the poor poorer (Kelly 2001a; Stillwaggon 2001).

**Stigma and isolation:** Affected people are stigmatized and may be prevented from gaining access to social support mechanisms. HIV-related stigmatization is responsible for social rejection, alienation, and can compromise employment, housing, schooling and child care. It means that HIV-related loss of family and friends is not likely to be acknowledged. Fear of isolation is particularly strong among teachers who live and work in small communities, where confidentiality is problematic.

**Psychosocial stress:** The disease brings with it psychosocial stresses. Illness and the prospect of death in the family, often not discussed with children, are as traumatic for the child as for the adult. Children are highly traumatized by watching parents die and not being able to talk about it. Stress and depression can compromise function and well-being in all areas of family life including school and work performance, family relationships and capacity for child care. Responses to stress may include alcohol and drug abuse and unsafe sexual behaviour. The difficulty here is that little is known about how children and young people process the stresses that engulf them (Solomon 2001; Ebersohn and Eloff 2001; Devine and Graham [n.d.]). This is the backdrop against which the challenge of HIV to education services is being played out in the high-prevalence countries of sub-Saharan Africa. It is these factors that will ultimately determine the profile of learner and educator populations and the supply of and demand for education (Collins and Rau 2000).

### Education demand and supply in high-prevalence countries

**Evaluating the evidence:** Isolating and assessing the consequences of HIV for education services in high-prevalence low- and middle-income countries is difficult for a number of reasons. There is no way of knowing exactly why children drop out of school. It is only possible to guess at reasons for changes in enrolment, progression, completion and dropout rates by using, with caution, what data are available. Use is also being made of anecdotal evidence and the observations of educators and social workers, and proxy measures like social welfare orphan registrations, rising incidence of child abuse in paediatric units and prevalence among school-age rather than school-going populations.

Teachers are known to be ill, absent from work and dying, but HIV is rarely named as the reason. There is no official procedure for terminating the services of African teachers who are HIV-positive and who should be pensioned off for medical reasons. Nor is there any way of determining whether teachers who are dying do so because of AIDS, except that – as in Botswana and South Africa – certain graphic data ring alarm bells for demographers.
Accurate information is hard to come by. Figures are collected with difficulty, and provide a poor base from which to generalize. National statistics can mask local variations in prevalence, and therefore in levels of impact on individual districts and schools. In most affected countries, there are clearly risk ‘hot-spots’ that differ from the national average (Badcock-Walters 2001). For education, additional information that must be factored into the demand and supply equation includes the composition of the teaching force in terms of age, gender and marital status, relative salary levels, qualifications etc., but this information is often difficult to obtain (Crouch 2001a).

Added to this are puzzles related to what the statistics really mean. For example, it is often not possible to know whether shifts one way or the other are due to HIV or to fiscal adjustments (up or down), adverse educational policies, the influences of increasing or decreasing socioeconomic deprivation, increasing or decreasing levels of international development support, or some other factor. Observable changes in enrolment at primary and secondary level in Uganda, and to some extent in Malawi, are due to EFA-driven progress in improving levels of primary provision (see chapter 2). As more primary school places become available, more children attend. But with places at secondary level increasing more slowly and still falling short of demand, any place vacated by a student affected or infected by HIV will be taken up by another candidate, with the result that secondary enrolment figures will appear to remain stable, or even rise, as levels of secondary provision improve (World Bank 2000a, p. 59).

In the South African province of KwaZulu-Natal, where HIV infection rates are probably the highest in the world, changing regulations on age of entry have skewed grade 1 enrolment data. So the alarming drop of 24 per cent in grade 1 enrolment in the province in 2000 was possibly a combination of new age of entry regulations, increasing poverty (much of it related to HIV), and HIV-related reduction in school-age population. The relative proportions in the mix are impossible as yet to determine (University of Natal, Health Economics and AIDS Research Division 2001).

Virtually every prediction of the pandemic’s impact on education is surrounded with caveats. There is tension between those who prefer to rely on so-called hard data and those who rely on qualitative evidence derived from the experience of educators, social and health workers, police and faith-based organizations, home-based care volunteers, researchers and parents (Crouch 2001a). Either way, impact can remain invisible for long periods of time. For example, in a country or state of, say, 50 million people, with a service of 400,000 educators, a 10 per cent prevalence would mean that 40,000 were HIV-positive, at some point along the continuum from initial infection to morbidity and mortality, with or without access to drugs. With 30,000 schools, each school might have only one or two infected teachers. More probably, some schools would have no infections, while others might have many. The most severe critical-mass impact can be expected in future
because of the long lag between HIV infection and development of AIDS and death. That means infections in the 1990s, particularly heavy in South Africa and Botswana, for example, are not felt until the first decade of the millennium. Uganda, where the epidemic is thought to have peaked in the early 1990s at between 9–12 per cent, may already have passed through the worst of the AIDS phase. And so reports and perceptions of the size and quality of the pandemic differ radically.

It is only possible to estimate, to use the best data, information and models available and to test predictions again and again. It is nevertheless necessary to indicate the most probable trends for education in future with the onset of AIDS.

The following supply and demand analysis is based on a number of sources: the preliminary but systematic teacher supply analysis by Luis Crouch and colleagues in South Africa; the World Bank’s study of turbulence in four high-impact countries (Kenya, Uganda, Zambia and Zimbabwe); a review of Ugandan data by Parkhurst; assessments by Abt Associates of the impact of HIV on education sectors in Botswana and South Africa; preliminary analysis of data for KwaZulu-Natal province in South Africa by the Health Economics and AIDS Research Division of the University of Natal (HEARD); and the summary of case studies in eight sub-Saharan African countries by Michael Kelly for the Economic Commission for Africa/Africa Development Forum (Crouch 2001a; World Bank 2000a; Parkhurst 2000; Abt Associates 2001; LoveLife 2000; Badcock-Walters 2001; Kelly 2000a).

**Demand for education services**

**Size of learner populations:** HIV will affect the size of learner populations. Where prevalence is high, rising deaths among adults of reproductive age and declining fertility rates result in fewer children being born. Combined with increased mortality among children infected around the time of birth, most of whom die before they are five years old, this means there are fewer potential learners than there would have been without HIV. It is anticipated that Zimbabwe will experience a 24.1 per cent reduction in primary school age population by 2010, Zambia 20.4 per cent, Kenya 13.8 per cent, and Uganda 12.2 per cent (Abt Associates 2001, p. 4; World Bank 2000a, p. 3).

In Botswana, there are likely to be 860,000 young people under 25 by 2015, rather than 1.2 million if HIV had not intervened. There is already evidence that the 0–4 year age group is declining in absolute numbers, while the 5–9 year age group showed signs of starting to decline in 2001. Grade 1 intake, which appears to have been slowing for some time, declined by 3 per cent in 1998 (Abt Associates 2001, p. 4).

In South Africa, the number of potential learners is expected to decline if orphans and other vulnerable children do not enrol, delay enrolling, or leave school in large numbers. In general, children at risk or orphaned by AIDS, and those in
HIV-affected homes, are likely to be withdrawn from schooling and higher education. Children who have been orphaned are more likely to be denied education. In Mozambique, only 24 per cent of such children attend school, compared with 60 per cent of those with living parents. Children affected by HIV often perform poorly at school and their dropout rates in parts of Botswana are reported to be unacceptably high. These results are confirmed by the survey data reported in the country studies in this compilation (see chapters 2 through 6) (Kelly 2000a; Abt Associates 2001; LoveLife 2000, pp. 26–27; UNICEF and USAID 2000).

It is essential that the accuracy of demographic projections be monitored, their assumptions interrogated, and changed circumstances, like the provision of antiretrovirals, be factored into these equations. In the short term, planning will need to take account of reductions in enrolments as fewer children are born and many HIV-infected children fail to thrive or survive to school-going age.

**Demand for education:** HIV will influence demand for education throughout the region. Declining primary enrolment over the next decade will in turn translate into subsequent reductions of qualified candidates for high school and tertiary training. In South Africa, younger people are most severely affected by the disease, with around 60 per cent of all adults who acquire HIV becoming infected before they turn 25.

Botswana, South Africa, Swaziland, Zimbabwe and Zambia already have evidence of stagnating or declining enrolments, much of it very likely attributable directly or indirectly to HIV (Kelly 2000a; Abt Associates 2001). Observable factors likely related to changes in demand include fewer resources for education in HIV-affected households because of high death rates. Learners will be withdrawn from school as orphaning and poverty rise, or will not enrol because of fees and opportunity costs, and the need to care for those who are ill. Communities will be unable to provide support for schools as they did in the past, although some communities are already reacting positively by building community schools for their own children.

**More complex learner cohorts:** HIV is affecting the potential clientele for education services by creating large cohorts of orphans and other vulnerable learners (chapter 11). In most parts of the industrialized world, usually no more than 1 per cent of the child population is orphaned. In low- and middle-income countries, the proportion would normally be 2 per cent of the child population, and orphans (under 15s who have lost mother or both parents) could be absorbed into the extended family.

By 2010, it is estimated that maternal and double orphans will rise to more than 25 per cent of children in Zimbabwe, to nearly 19 per cent in Zambia and about 17 per cent in Kenya. The addition of paternal orphans and orphans from causes other than AIDS would raise the proportions for these countries even further (UNICEF 1999; World Bank 2000a, p. 7). By 2005, there will be 800,000 orphans under 15 in South Africa, rising to almost 2 million by 2010. The number of orphans in

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Carol Coombe
Botswana is projected to rise rapidly from 38,000 in 2000 to 161,000 by 2010 (current population 1.8 million) with one in two children aged 10–14 orphaned. Rates of orphanhood will be higher in some districts, schools and classrooms than in others. Some secondary schools in Botswana already report that 20–30 per cent of students in some classes are orphans (Abt Associates 2001).

In Malawi, during 1999, the percentage of children in school who had lost one or both parents increased from 12 per cent to 17 per cent. In one study, a third of the children reported they missed school in order to care for the sick. This percentage doubled for children who had lost both parents. And 6 per cent of children reported missing school for funerals. Children with both parents dead were twice as likely to drop out (17.1 per cent) during the 2000 school year as children with one parent dead (9.1 per cent), or both parents living (9.5 per cent). Repetition rates for children whose parents were dead were 5–15 per cent higher (depending on cohort and grade) than for children with living parents. The average age for pupils with both parents dead was about six months older than the average age in their grade cohort (Harris and Schubert 2000).

The consequences for education of large numbers of HIV-affected learners are likely to be profound. Such learners are often at physical disadvantage for nutritional and economic reasons. Their attendance and performance declines and they are likely to suffer HIV-related discrimination. Their attendance at school becomes increasingly random, and they must learn under a cloud of trauma and loss. When teachers suffer for the same reasons, and are unable to respond to the needs of children in distress, decline in motivation, morale and performance on both sides is inevitable.

Supply of education services

Predicting basic supply and demand for teachers is virtually impossible. While the demand side may be relatively easy to forecast, the supply – and therefore the gap between supply and demand – is much less straightforward (Crouch 2001a, p. 28). Nevertheless, it is remarkable that, at a time when the business community in high-prevalence countries is being forced to assess the potential impact of HIV on workforces, and attendant cost and inefficiency problems, governments have given little or no attention to protecting the education service, the largest, most expensive and highly trained cohort of workers in any low- and middle-income country (Moore and Kramer 1999, p. 4).

Increased educator morbidity and mortality: HIV will affect the supply of education services through increased mortality of educators. The World Bank assumes very generally that losses of educators will parallel those in adult populations. Zimbabwe would therefore lose about 2.1 per cent of educators to AIDS between 2000 and 2010, Zambia and Kenya 1.7 per cent and 1.4 per cent, and Uganda (where AIDS
mortality appears to be lower) an estimated 0.5 per cent (World Bank 2000a, p. 5). The Zambian Ministry of Education reported that 2.2 per cent of all teachers died in 1996. This was already more than the number of teachers produced by colleges that year, but it has been estimated that teacher death rates might triple by 2005 (LoveLife 2000). The World Bank reported a study that projected 14,460 Tanzanian teachers would die by 2010, costing $21 million in replacement training (Save the Children UK 2001a). Crouch’s stylized projections for South Africa suggest that, whereas teacher education production capacity is now 5,000 annually, at least 30,000 new teachers will need to be trained each year by the end of the decade (Crouch 2001b).

Kelly (2000a) and others⁴ suggest that the educator cohort is at high risk of infection because of their relative affluence, mobility and status in the community, their expectations of sexual ‘bonuses’ in lieu of better conditions of service, and circumstances that separate them from their families.⁵ However, recent analysis suggests that for teachers, as for other professionals, early high incidence rates are reducing gradually to below-average rates (Botswana Ministry of Education 2000; Abt Associates 2001).

Death rates in excess of 3 per cent of educators per year have been reported in at least two countries (Abt Associates 2001). There are indications that primary school teachers are at greater risk than secondary educators. Teachers are also being lost to other sectors of government and to the private sector to replace personnel lost to AIDS (Swaziland Ministry of Education 1999). Educator productivity is reported to be down and absenteeism up because of HIV-related sickness, care for family members and attendance at funerals.

**Increased costs of provision:** HIV will affect the supply of education services because of the costs it imposes on the system. In Botswana, direct costs of HIV to education include employee benefits, hiring of temporary staff, and costs of recruitment and training. Indirect costs include loss of productivity due to absenteeism, loss of skills, declining morale and low performance among ill employees. Most studies indicate that the impact on organization function and costs is seldom disastrous in any one year, unless a key official is lost at a critical time. The greatest concern is for the relentless loss of skills that build up to a significant human resource deficit, and gradual decline in quality.

For Botswana, possibly the only country where these calculations have been done for the education service, Abt Associates suggest that if the total education workforce were provided with ARV treatment, medical costs might well exceed 0.9 per cent of the basic salary bill by 2005, and 1.8 per cent in 2010. Pension funds are structured in such a way that the cost implications of illness and deaths to the sector are neutral. There is concern, however, that levels of benefits provided to employees who are ill or die could be considered inadequate. Benefits currently give sick employees a financial incentive to stay in post until they die, even though this is clearly undesirable for them and their families, as well as for learners and colleagues (Abt Associates 2001).
Balancing demand and supply: Through 2010, HIV will likely affect the demand for educational services somewhat more than the supply. It is probable, on the basis of statistical analysis for Kenya, Uganda, Zambia and Zimbabwe, (1) that fewer teachers will be needed because the school age population will be smaller, and (2) that fewer teachers will be available because of increased teacher mortality. This is a very tentative conclusion, because the calculation on which it is based does not take into account teacher absenteeism and early mortality caused by opportunistic infections, or many of the other complex panoply of factors that influence educator supply and learner demand (World Bank 2000a; Crouch 2001a).

Challenges to education quality

The HIV pandemic will affect the quality of education services. Teachers are being lost through illness and mortality (Botswana and KwaZulu-Natal), and transfers to other sectors (Swaziland). HIV-related illness means educators become increasingly unproductive. Death or absence of even a single educator is particularly serious because this affects the education of 50 or more children. Because teaching service management has made no provision for medically boarding educators who are ill (and may refuse to be tested), teachers continue to teach even during terminal illness (Botswana and South Africa). With high teacher and pupil absenteeism, instructional time is disrupted. Textbooks and teachers’ manuals are designed for a full school year of full-class instruction. There is no evidence that provision is being made for individual learning or for adjusting lessons to learner needs. Repetition is not the answer, for this merely increases class size, reduces efficiency, and puts girls at risk when older boys join the class (LoveLife 2000; Harris and Schubert 2000; Caillods 2000).

Current shortages of educators in critical fields such as science, mathematics and technical skills will become more acute. Loss of key individuals in management or senior leadership – planners, principals, inspectors, teacher educators – may compromise quality and efficiency. Concentration of deaths among staff in the 30–39 year age group, just when they have accumulated important experience, means not only loss of their skills but may jeopardize less formal processes of mentoring and skills transfer within the sector.

As the average age and experience of teachers falls, systems will rely increasingly on less qualified teachers and there are likely to be fewer secondary school graduates able to enter teacher education (LoveLife 2000).

HIV is impacting on the emotional status of educators and young people (Kelly 2000a). Teachers who, at least in Africa, have generally resisted voluntary testing and counselling may be uncertain about their own HIV status (Abt Associates 2001). Both educators and learners have difficulty concentrating in the face of illness, death, mourning and dislocation (Kelly 2000a). Many learners affected by the presence of HIV have
a widespread sense of anxiety, confusion and insecurity (Devine and Graham [n.d.]; Ebersohn and Eloff 2001). The psychosocial needs of affected children are not as well understood as their material needs (UNICEF et al. 2001; Save the Children UK 2001a; Coombe 2001b). Adult caregivers may fail to identify psychological difficulties as the cause of more visible problems like truancy or anti-social behaviour. And where emotional problems do manifest themselves, few people responsible for children are equipped to handle them. Further, where abuse and violence, along with teacher misconduct, characterize the learners’ community, young girls and boys fear they will be sexually abused or maltreated. There may be uncertainty and distrust between learners and educators if the latter are seen to be those responsible for introducing or spreading HIV (Leach and Machakanja 2001; Kelly 2000a).

Overall, the HIV epidemic results in considerable stress, and contributes to what one educator described as the ‘inchoate unease’ that textures the learning environment in heavily infected countries (Harris and Schubert 2000). Not all schools will suffer to the same extent. But there is enough personal and systemic trauma to undermine education quality generally.

Finally, and ironically, policies intended to support children affected by HIV, such as Malawi and Uganda’s introduction of free primary education for all children, have dramatically overstretched the education system and reduced quality of provision.

**Current education responses to HIV**

Responses to the pandemic vary worldwide, according to infection rates, geographical, cultural and religious variables, the leadership and management capacity of governments and the level of commitment in non-government sectors. Where prevalence is low, or confined to high-risk groups, there is little evidence of concern in the education sector as the systems are not yet confronting large numbers of HIV-affected learners or high teacher attrition.

This analysis of current policy responses therefore concentrates on experience in high-prevalence countries, mainly but not exclusively in sub-Saharan Africa and the Asia–Pacific Region, in helping to contain the epidemic’s spread, providing social support for affected learners and educators and protecting the education system. The review focuses principally on the response of the official or formal system, although it emphasizes the increasing role being played by non-government agencies and the importance of strengthening their contribution to the response to AIDS.

**Containing the spread of HIV among children and adolescents**

Governments in high-prevalence countries have accepted responsibility for delivering mass prevention campaigns through learning institutions and non-government
partners. While the aims of such campaigns can be categorized, their actual achievements are poorly described in the literature and are very rarely evaluated. Much supplementary prevention work is carried out by communities, NGOs and faith-based organizations (FBOs), with support from the international community. What follows is a description of what is known from observation, experience, case studies, information from conference reports, a survey of Southern African Development Community (SADC) ministries of education, and so-called grey literature.

Developing lifeskills curriculum and learning and teaching materials: The teaching response to HIV (known as HIV education, reproductive health and sex education, life skills or life orientation)\(^7\) is generally supposed to communicate relevant knowledge, engender appropriate values and attitudes and build personal capacity to maintain or adopt behaviour that will minimize or eliminate the risk of becoming infected by HIV. An indirect benefit of such programmes is that teachers too, lacking educator-focused prevention programmes of their own, learn about HIV. Curricula generally aim at equipping learners with skills such as decision-making, problem-solving, effective communication, assertiveness, and conflict resolution (Kelly 2000a).

Most countries in Eastern and Southern Africa have either elaborated HIV-related curricula or are ‘planning to do so’. Questions persist about whether to include life skills and reproductive health in the school curriculum as a separate subject or integrated in other subjects. There is ubiquitous evidence that few teaching and learning materials are getting into classrooms, and that teachers have virtually no guidelines for coping with the pandemic (Berkhof 2001).

Youth-focused media campaigns like LoveLife and Soul City in Botswana, Namibia and South Africa, (see www.comminit.com) the media campaign of the Johns Hopkins University unit in Rwanda, the Sara programme in the United Republic of Tanzania, and the Red Cross AIDS Network for Youth (West Africa) (Adu-Aryee 2001) effectively supplement school-based and college-based HIV programmes. But media campaigns focused at young people in Africa have for the most part tended to be limited in coverage, poorly designed and disseminated and sometimes thematically inappropriate where they fail to take account of adolescent and contextual realities.

Providing guidance on the distribution and use of condoms: The idea of condoms for young people is a persistent cause of conflict between ministers and their constituencies, between parents and teachers and between teachers and students. There is no evidence that guidance on condom availability, accessibility and use has been issued to teachers or school heads in any country surveyed. Resistance by faith leaders, older teachers and traditional leaders has created an aura of ambivalence.

To avoid such ambivalence and confrontation, Uganda is reported to have waged a ‘silent campaign’ during which, without public debate, condoms were made available
to those who needed and wanted them. The Thai 100 per cent condom programme succeeded because it concentrated on a limited goal and excluded questions of morality or the elimination of prostitution. ‘Other countries would do well to consider this aspect when drawing up their own programmes.’ (Larson and Narain 2001, p. 35). Difficult decisions about condoms will need to be made by young people and their parents and by communities and school governing bodies locally, rather than by central authorities.

**In-service and pre-service preparation of educators:** Sub-Saharan African education sector strategic plans commonly ignore or fail to address the need to adjust INSET (in-service teacher education) and PRESET (pre-service teacher education) programmes, their curricula, delivery and purpose and the urgent importance of adjusting guidance manuals and teaching/learning materials appropriately. A review of university and college-based teacher education programmes in South Africa demonstrated recently that, while some institutions were ‘thinking about’ preparing to teach HIV curricula, most had done little or nothing to move in that direction.8

Thirteen of the 14 countries in the Southern Africa Development Community (SADC) region were surveyed in February to March 2001 about their response to the pandemic (SADC 2001).9 The ministries of education reported as follows:

<table>
<thead>
<tr>
<th>Helping to limit the spread of AIDS: the SADC region</th>
<th>Y</th>
<th>P</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appropriate curriculum in all learning institutions:</strong></td>
<td>2</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Are learners being guided through the curriculum on safe sex and appropriate behaviours and attitudes?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Materials developed and distributed:</strong> Have materials suitable for learners in schools and post-school institutions been developed and distributed to institutions? Are they up to date?</td>
<td>1</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td><strong>Serving educators prepared:</strong> Are school teachers adequately prepared through pre-service and in-service training to teach life skills curricula? Have they accepted this responsibility?</td>
<td>2</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td><strong>Teacher educators prepared:</strong> Have university, teacher training college and local teacher support staff been trained in HIV and AIDS issues and curriculum implementation?</td>
<td>0</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td><strong>Evaluation of curriculum and materials:</strong> Have materials and courses been evaluated in terms of content, implementation and outcomes?</td>
<td>1</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td><strong>Partnerships:</strong> Are other partners helping with prevention programmes?</td>
<td>0</td>
<td>9</td>
<td>4</td>
</tr>
</tbody>
</table>

Y Yes, action is being taken   P Some action is planned   N No action is being taken
An analysis of case studies from Ethiopia, Kenya, Malawi, Rwanda, South Africa, Uganda, United Republic of Tanzania and Zimbabwe for the United Nations Economic Commission for Africa (ECA) highlights the shortcomings of current prevention programmes in the subregion (Kelly 2000a). Most programmes start too late, for children aged nine and up. They are developed from the top with little consultation with parents, teachers or young people, and are more concerned with the biology of human reproduction and barrier methods of prevention than about understanding relationships, showing respect for others and protecting the rights of all. Delivery is almost exclusively in the hands of teachers, although they are for the most part poorly prepared. The discredited cascade model used to train them (if they receive training at all) often dilutes or even misrepresents content. Many teachers are poor role models and feel uncomfortable talking about sexuality. Cultural beliefs, expectations, traditions and taboos related to behaviour receive little attention, and materials generally portray sexuality as heterosexual and consensual, ignoring problematic issues of rape and harassment and rising levels of incest, homosexuality and child abuse. Finally, there has been no effective evaluation of programme content, implementation or outcomes, and the extent to which such programmes reduce HIV transmission, STIs, rape or coerced sex is unknown.

**Constraints to prevention efforts:** While HIV prevention delivered through schools is agreed to have potential for helping to keep children and young people safe, and allowing them to help others, its potential is not being realized for a number of reasons (Inter-Agency Working Group 2001; Kelly 2000a; Coombe 2001a).

In many countries, sexuality education cannot, for religious reasons, be part of the educational curriculum. Talking about sex publicly continues to be taboo in much of Pakistan and China, for example, where illiteracy and school exclusion rates continue to be high.10

In many communities, the belief persists that any kind of sexual education leads to increased sexual activity, but African case studies confirm what has been found elsewhere: young people who participate in reproductive health programmes do not become promiscuous. They do not engage in sex earlier or seek more frequent sexual intercourse, and in some cases even delay initiation of sexual activity (Kelly 2000a).

When behavioural changes fail to appear quickly, the assumption is made that the programme has failed. Clearly HIV prevention education, to be successful, must be complemented by a range of consistent, long-term, supportive strategies. It is discouraging to note that in Botswana, ‘antenatal survey data and various surveys of knowledge, attitudes and practices indicate that despite high levels of awareness of AIDS and basic HIV/AIDS knowledge, there has been no change in behaviour that seriously begins to turn back the pandemic’ (Abt Associates 2001).
HIV is only one of many problems faced by education services. Failure to deliver prevention messages effectively is compounded by the dire physical environment of many schools (lack of water, latrines, adequate classrooms and teachers’ housing, decent hostels, furniture and books), by the teacher- and child-unfriendly ambiance in many learning institutions (where physical and sexual abuse are present, along with corporal punishment and trauma related to poverty or HIV), and by inadequate management support for teachers (overcrowded classes, low and irregular salaries, policies that may discriminate against HIV-affected learners and educators, and comprehensive failure to provide for educators affected by HIV) (Coombe 2001c).

Social support: care and counselling for learners and educators affected by HIV

Although they are ‘less tangible than the violations of other rights that children suffer, psychosocial problems are rarely addressed in HIV/AIDS programmes, and yet can have long-term impact on development. A child’s progression through basic developmental stages is jeopardized if HIV-related illness reduces, and then ends, a parent’s capacity to provide consistent love and care’ (UNICEF et al. 2001, p. 8). Adequate socialization might have been added to the list.

Little is known in practice about how children and their families are coping with HIV-related trauma and the impact it has in the classroom (Ebersohn and Eloff 2001). The SADC review graphically demonstrated the failure of countries to provide even a modicum of social support in schools or to engage with the likely consequences of having increasing numbers of intellectually, socially and psychologically dysfunctional learners:

<table>
<thead>
<tr>
<th>Providing social support: SADC region</th>
<th>Y</th>
<th>P</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Counselling for learners</strong>: Can pupils and students who are affected by AIDS find help from their teachers?</td>
<td>0</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Or from someone else?</td>
<td>0</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td><strong>Social support</strong>: Are children affected and infected by the pandemic receiving counselling and care? Is there a culture of care in schools and institutions?</td>
<td>1</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td><strong>Orphan needs</strong>: Is planning under way to understand and respond to the special needs of increasing numbers of orphaned and other vulnerable children?</td>
<td>1</td>
<td>5</td>
<td>7</td>
</tr>
</tbody>
</table>

Y Yes, action is being taken    P Some action is planned    N No action is being taken
There is substantial evidence from principals and teachers that non-government agencies are providing support to schools through peer group programmes, teacher advice and counselling, and training. Such programmes are generally ad hoc, often grossly underfunded relative to the role they play (or could play) and are not generally recognized, resourced or formally contracted by the official system to undertake tasks that the system itself is apparently not capable of doing.

**Challenges**

The education sector’s responsibilities vis-à-vis HIV need defining. With concentration focused on prevention programmes, there has been no clear definition of the sector’s role in social support, or of schools’ role in local strategic planning. Although many teachers, especially women, are responding generously as individuals, the education service generally does not promote social support. And guidance and counselling programmes are not a suitable alternative. There is potential for forming a circle of care network involving education, social and health systems, but for the most part there is poor coordination among social sector staff at all levels, and between them and local volunteers.

**Protecting education quality**

In any country, the education budget commands one of the largest slices of the national fiscus. Nevertheless, government managers have been, perhaps inexplicably, slow to take action to maintain efficiency, sustain output and reduce cost in the face of this pandemic.

Education sector ‘strategic plans’ are widely variable in the extent to which they recognize and incorporate (if at all) the turbulence caused by HIV. The Cambodian Strategic Plan 2001–2005 is limited to prevention measures (Cambodia Ministry of Education 2001). Botswana, Namibia and Zimbabwe are currently assessing the impact of HIV on the sector, and Zambia has prepared an HIV strategy within the context of its sector-wide approach (SWAp) programme. In Kenya, projections used for education planning take account of likely HIV impact scenarios but are not factored into planning. In Uganda, though official projections incorporate assumptions about HIV, planning projections in the ministry are based more on assumed intake and repetition rates than on projections of the size of the school age population and assumed enrolment ratios during a period when Uganda is moving strongly toward UPE goals (Abt Associates 2001; World Bank 2000a).

Evidence from both SADC and Economic Community of West African States (ECOWAS) (Baku 2001; Casely-Hayford 2001) regions shows that current HIV and education strategic plans concentrate on curriculum interventions aimed at behaviour change. They focus principally on primary and secondary schools to the exclusion of early childhood development, post-secondary training, the university and college sector and out-of-school children. They generally fail to address issues related to the management of the teaching service affected by HIV (Ghana and South Africa may
be exceptions) and the needs of learners affected by HIV. Perhaps the implications are too large and too complex. Although the South Africa Education Department included workplace policy as one of the eight pillars of its 2001–2002 HIV plan, there is little other evidence of such policies elsewhere in the region. Current teaching service regulations and human resource management policies need major review.

Finally, and fatally, there is no observable attention being given to the managerial capacity, funding, human resources and infrastructural requirements that need to be in place to support practical strategic action in the sector (Association for the Development of Education in Africa 2001).

SADC evidence demonstrates the extent to which most ministries have failed to address the planning and management complexities that HIV imposes (Coombe 2001d).

Table 3. Mitigating the impact of HIV and AIDS on the education sector

<table>
<thead>
<tr>
<th></th>
<th>Y</th>
<th>P</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assessment:</strong> Has an assessment been done of the likely impact of HIV and AIDS on the education sector in future?</td>
<td>4</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td><strong>Risk profile:</strong> Is there some understanding of the factors that make educators and learners vulnerable to infection?</td>
<td>0</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td><strong>Stabilizing:</strong> Are steps being taken to sustain the quality of education provision and to replace teachers and managers lost to the system?</td>
<td>0</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td><strong>Projecting:</strong> Have relatively accurate projections been made of likely enrolments and teacher requirements at various levels of the system over the next 5 to 10 years?</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td><strong>Responding creatively:</strong> Is the system trying to provide meaningful, relevant educational services to learners affected by HIV, finding new times, places and techniques for learning and teaching?</td>
<td>0</td>
<td>0</td>
<td>13</td>
</tr>
<tr>
<td><strong>All subsectors:</strong> Is attention being paid to the planning requirements of all education subsectors – from early childhood development through to university?</td>
<td>0</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

Y  Yes, action is being taken  P  Some action is planned  N  No action is being taken

Responding creatively to more complex learning needs

At the same time as educational systems and institutions become more fragile, appropriate learning opportunities will need to be created for multitudes of children
who have been orphaned by AIDS or are otherwise vulnerable. That means, for example, making special learning provision for orphans suffering disorientation or isolation, for children caring for younger children, and girls caring for the sick. Young people and selected teachers will need to learn basic caring and counselling skills so they can help those in physical or emotional difficulty. Alternative learning opportunities are required for those forced out of school early or who need to move in and out of learning. This probably means moving in the direction of a lifelong learning paradigm and a broader and fresher definition of ‘nonformal education’.

Schools have a critical role to play as centres of support for communities in the grip of HIV (Kelly 2000a). There is growing recognition among policymakers and educators that each school can be a fulcrum for community welfare. That means working more closely with health and social services, and providing a physical focus for community effort (including providing fax, phones and electricity in some instances). But as educators are already under pressure from HIV, and are having enough difficulties delivering basic HIV-related knowledge, being creative may be a step too far. To expect them to make a swift transition to providing care and counselling is unreasonable. Most schools are very basic places, with far too many problems already.

Evaluating current responses

Many countries around the world have established national AIDS councils and secretariats and HIV units in their ministries of education, though they are typically understaffed and lack executive power. There is extensive political commitment at the highest level in countries like Botswana and Uganda, although others like South Africa, for example, have fallen short in this regard. Many countries are now emphasizing a multisectoral approach that deals with HIV as a development issue that transcends health. It is difficult to ascertain whether governments are keen to hand to communities because they know local strategies can work, or because they recognize the problem is too big, too costly and too complex for central government to handle.

Several countries have commissioned education sector impact assessments (Botswana, Mozambique, Namibia, South Africa, Swaziland, Zimbabwe) and have created HIV and education policy and strategic plans. But implementing such plans reveals persistent management weakness. Most managers have not received professional preparation for their responsibilities and many hold posts by virtue of their seniority or experience gained as they rose through the ranks. HIV is wreaking havoc with fragile management systems (Kelly 2000a).

The SADC survey summarizes the consequences of inadequate management capacity.
Table 4. Creating a foundation for action

<table>
<thead>
<tr>
<th></th>
<th>Y</th>
<th>P</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Combined approach:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is equal consideration given to (1) preventing spread of the disease and to (2) reducing the anticipated impact of the pandemic on education?</td>
<td>3</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td><strong>Leadership:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are political leaders, senior officials, unions, the teaching service and school governing bodies knowledgeable and committed to action?</td>
<td>4</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td><strong>Collective dedication:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are partners outside government involved in the fight against HIV and AIDS? Do mechanisms exist for partnerships?</td>
<td>4</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td><strong>Research agenda:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is information about HIV and AIDS being collected, analysed, stored and spread? Is there an HIV and education research agenda for the education sector?</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td><strong>Effective management:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has a full-time senior manager been appointed? Does a standing structure exist that includes partners in and out of government?</td>
<td>5</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td><strong>Policy and regulations:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are HIV sector policies and regulations in place? Are there appropriate codes of conduct for teachers and learners, and are they applied rigorously?</td>
<td>1</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td><strong>Strategic plan:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is there an education sector HIV and AIDS strategic plan that covers all levels of the whole education sector, and is it funded?</td>
<td>2</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td><strong>Resource allocation:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are plans being funded adequately? Are funds being channelled to various levels of the system, and to partners outside government who can use them?</td>
<td>2</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

Y  Yes, action in being taken   P  Some action is planned   N  No action is being taken

There is much to be done. What are the priorities for action, and how can they be achieved?

‘Best practice’ responses

This section examines what seem to be effective strategic principles, significant interventions, and successes of education services worldwide. To do so is daunting, because there is still little hard evidence, especially from governments, about what
works and what does not. Behavioural change is a complex process, and so even when declining prevalence or incidence can be traced to such changes, it is difficult to identify the direct causes. Such studies as there are usually test the impact of health or medical interventions, such as STI treatment, rather than the impact of any government information and HIV prevention campaigns (Parkhurst 2000).

There is danger in generalizing from one country’s set of data, because data collection and analysis may be flawed, and because what works for one place may not work for another (Webb 2001). The Cambodian and Thai epidemics, for example, have not followed natural epidemiological history: behaviour change was widespread and prevalence peaks of 2–3 per cent did not represent the pre-existing potential of the epidemic, given the favourable climate for its spread. It is therefore not possible to assume that other countries can limit the pandemic in the same way (Brown 2001). In addition, interventions that work in a country with low incidence rates, and succeed in keeping them low (UNAIDS/FHI 2001), may not be appropriate in a community or country with high prevalence, where the pandemic is already out of control.

The case of Uganda

Concern has recently been raised about what can be learned from the anomalous success of Uganda. In his analysis of Ugandan data, Parkhurst stresses that, to learn from the evidence, it must first be understood that a decline in prevalence or incidence does not necessarily reflect changes in behaviour or intervention effects (Parkhurst 2000). While the HIV-response community has regularly cited the success of the Government of Uganda in controlling its HIV pandemic, ‘Unfortunately, there is often a lack of detailed explanation of what these HIV rates actually indicate, and what the Ugandan Government might have done to achieve any apparent declines’ (Parkhurst 2000).

Statistical analysis of the Ugandan pandemic and its impact is extremely complex, so assumptions that it is possible to learn from its purported success, and to apply evidence of ‘best practice’ there to other countries, may be fatally flawed. Parkhurst argues that researchers and the press alike may have misinterpreted or misused Ugandan data and evidence. Repetition of commonplace errors has created a ‘myth’, which supports the current international belief of a Ugandan success story. Calls to emulate Uganda rarely examine possible biases involved in the epidemiological data. Other nations facing HIV prevalence of 30 per cent cannot simply copy the Ugandan policy response and achieve a two-thirds reduction in their national prevalence. Yet, Parkhurst argues, authors imply emulation is possible when they claim Uganda’s infection rates decreased from 30 per cent to 10 per cent, attribute this drop to the actions of Government, and call upon African nations to adopt a similar response to bring their own HIV epidemics under control (Parkhurst 2000).
No one can quite determine why Uganda’s prevalence has dropped so quickly (World Bank 2000a). While agreement exists on the reality of the decline in HIV prevalence, no one has been able to link behavioural change to any particular programme intervention. And if information diffusion has been key to Uganda’s success, the education sector has evidently not been a major player. HIV programmes in schools began as early as 1992, and a few activities – HIV and AIDS drama, for example – have been used extensively. But Ugandan education officials say that school- and teacher-oriented programmes have not been particularly strong. The ministry is now ‘looking to strengthen programmes so the sector can play a more active role in addressing the epidemic’ (World Bank 2000a).

Elements of good practice

Is it therefore possible to identify a set of principles and models that constitute ‘best practice’? A study of presumed HIV prevention success in Senegal, Thailand and Uganda (UNAIDS 2001) suggests that successful national HIV programmes share common features:

- strong political commitment;
- early intervention/prevention;
- intensive multisectoral approaches at national, provincial and community levels;
- implementation on a large scale;
- effective monitoring and dissemination of findings to sustain awareness; and
- combined prevention and care.

Unfortunately, the three-country review extrapolates little of practical use in terms of best practice. It modestly suggests that prevention can work if properly implemented, but monitoring and research are needed, and policymakers and international and local communities need to see that investment is paying off. The most important message for low-prevalence countries is that prevention must begin before HIV prevalence grows to measurable levels.

Reality checks and strategic principles

HIV and education strategic plans based on sound policy and a realistic assessment of available capacity are essential for counterattacking AIDS (Hunter and Williamson 2000). Principles to guide strategic planning and action in the sector can be summarized as follows.

i) Governments cannot by themselves protect education services but must work with all other stakeholders in the education community – NGOs, parents and
traditional leaders, CBOs and FBOs, international agencies and volunteers – as well as with social sector departments at national, provincial and community levels.

ii) Effective responses are usually those that are locally devised to meet local conditions, and this principle seems to underlie success. Knowledge, behaviours, attitudes and understanding exist within a complex set of cultural values and economic circumstances that must inform planning and action.

iii) Local responses must be complemented by vigorous, extensive and intensive national programmes relating to condom use and STI prevention, life skills curricula in schools and support for children orphaned by AIDS, in order to reach as many people as possible. Rigorous coordination of local programmes within a national policy framework might achieve similar results.

iv) Many governments are managerially challenged. It is essential to choose interventions that are within the competence of the system to deliver. If simple tasks are successfully managed, they will contribute to building an environment that will make more challenging interventions possible at a later stage (Marais 2000).

v) Educators may not always be the best people to deliver vital messages about death and sex, behaviour change and risk. Young people, on the other hand, have often been at the forefront of successful change (Devanney 2001).

Adjusting the legal and regulatory framework

The challenge of AIDS requires that all education legislation, policy, regulations, codes and statutes be reviewed for at least two reasons. First, it is necessary to identify the rights and responsibilities of individuals and agencies. Second, it is essential to adjust laws and regulations antithetical to the promotion of rights, particularly of women and children. The South African Law Commission undertook a complete review of existing legislation for the Department of Education before its policy on HIV and AIDS was promulgated.

The Commission’s Consultative Paper on Children Infected and Affected by HIV/AIDS (1998) specified that learners with HIV should not be unfairly discriminated against, that no learner should be denied access to school on the basis of his or her HIV status, that testing of learners for HIV for admission to or attendance at school would be prohibited, that needs of learners with HIV should be accommodated within the school environment, that a learner’s HIV status should be confidential and not be disclosed without consent, that all schools should implement universal precautions to eliminate the risk of transmission of blood-borne pathogens including HIV in the learning environment, and that HIV education programmes should be implemented at all institutions for learners, educators and other staff (Smart 1999).

It is also necessary to check teaching service regulations, codes of conduct and
government general orders relating to the service to keep them in line with changing conditions (Ndubani 2001). Although teaching service management in Botswana and Zambia is stretched to the limits by high levels of infection, little has been done to address these issues.

**Helping to contain the spread of HIV**

The first thing to do is to ‘recognize that for 20 long, hard years we have lived with this epidemic which is causing unspeakable human suffering, entrenching poverty, subjugating women, and unravelling development efforts. Recognize that we know what to do. Recognize that we know how to protect our education systems. Recognize that with these systems protected, education has the potential to stem the further spread of the disease and to assist individuals in coping with its impacts. Recognize that what is needed is action’ (Coombe and Kelly 2001).

Global prevention targets have been spelled out in the *Declaration of Commitment on HIV/AIDS* (United Nations 2001). It is clear that prevention can work if the response is quick, intensive and extensive, and if it mobilizes all stakeholders in the public, private and community sectors. Education’s first responsibility is to educate learners on sexuality, reproductive health and prevention of STIs and HIV before they become sexually active (Larson and Narain 2001, p. 32).

**The life skills approach:** Mainstreaming, strengthening and extending life skills programmes are essential (Carr-Hill et al. 2001). Current life skills programmes may not be working well (in the SADC region, for example, see above), but they can be made to work.

Thailand’s success in reducing incidence rates is often attributed to school-based IEC programmes, but such programmes will not change behaviour where they are ineffectively implemented. Teaching and learning materials must be relevant and available in all learning institutions. Teachers and other educators must be prepared through INSET and PRESET to talk about issues that may customarily be taboo. Communities must be mobilized to understand and support the work of educators (Life Skills Development Foundation 2001).

Where it is difficult or taboo to teach life orientation programmes, including sexuality education, because of cultural, religious or customary perceptions, alternatives to conventional life skills curricula are being sought. Value-based approaches to HIV awareness are being used effectively in Botswana among very young primary school children, and in Pakistan where the *Aware for Life* curriculum focuses on adults’ and children’s rights and responsibilities as a way of sustaining behaviour change. In both countries, involvement of young people, parents, teachers and community elders in the value-based approach is deemed to be essential (Save the Children UK 2001b).
Ultimately, however, the life orientation approach can only take root where there is a climate in learning institutions that affirms the principles of respect, responsibility, rights and transparency, and which, more fundamentally, projects an image of good sanitation, safe water and good general health.

**Educating the teachers:** It is assumed that teachers will be at the forefront of the response to HIV, but they need to be equipped. In South Africa, the Department of Education’s *HIV and AIDS Emergency Guidelines for Educators* sets out HIV facts and eight key messages about preventing HIV and related discrimination, deals with questions educators ask about sexuality education, advises on universal precautions and how to build a school culture of non-discrimination. It offers helpline numbers and channels to other support services (South Africa Department of Education 2001b).

Pre-service and in-service programmes offered by universities and colleges need to be adjusted to take account of new classroom realities, including increasing numbers of disadvantaged and traumatized children and illness and absenteeism among learners and educators. INSET structures are very rarely robust anywhere in the developing world, and they are able to do little, despite reported successes in a few places like Karnataka State in India and the Western Cape Province in South Africa, to prepare large numbers of serving teachers to cope with HIV at school. Crouch (2001a) estimates that South Africa will have to train at least 30,000 new teachers per year by 2010. The current output is only around 2,000.

Teaching and learning materials are needed to guide teachers, heads of institutions and parents on dealing with HIV issues with children in their care. *Securing a Future: Mekong Children and HIV/AIDS* is a good example of material prepared for those working with younger children (UNICEF East Asia 2001a); see also *HIV/AIDS Handbook for Christian Caregivers* (Rwanda Christian Counselling and Training Centre 2001) and *HIV and AIDS: Care and Support of Affected and Infected Learners: A Guide for Educators*, which is a useful resource for South Africa’s teachers and others working with children in trauma (South Africa Department of Health 2001). Every educator should have a personal copy, however cheaply produced, of a booklet setting out the aetiology of the disease (Visagie 1999, for example), because educator ignorance about the nature of the virus, transmission modes, precautions and basic therapy for affected children is universally and abysmally high. It is crucial to develop appropriate educational materials and make them easily accessible to all concerned.

Finally, educator training and sensitization needs to be done in conjunction with development of workplace policy, workplace prevention programmes (every learning institution is a workplace) and impact management programmes. The *ILO Code of Practice on HIV/AIDS and the World of Work* has been tabled and is suitable for adaptation to local circumstances (International Labour Organization 2001).
Youth awareness – using the energy of young people: Children and adolescents are part of the solution to AIDS. They need to be involved in the design and delivery of prevention programmes through peer school health teams, local and international NGO programmes, and anti-AIDS clubs. UNAIDS reports that, where HIV prevention has been successful, young people have been at the forefront of change. In Rwanda, a recent evaluation of anti-AIDS clubs demonstrated their potential, and the advantages of youth working with youth, a strategy also being promoted in Rwanda by PSI. The AIDS Task Force of Fiji works with peer educators throughout the Pacific Region. Peer educators from Kiribati, the Marshall Islands, Nauru, Samoa, the Solomon Islands and Tonga have been trained in outreach work, interpersonal skills and HIV issues and they help to train other peer educators. They are known for their commitment and dedication, although there is concern that they only have the knowledge and skills to give information about the virus and are not trained to instigate behavioural change (AIDS Task Force of Fiji 2001, p.14).

Women and girls – putting them first: The United Nations General Assembly Special Session on HIV and AIDS made special reference to the vulnerability of female pupils and educators. Women must therefore be empowered to make decisions and take control over their lives and sexuality, and measures need to be put in place to protect them from sexual violence and abuse (United Nations 2001).

Retaining learners – education as a vaccine: School is like a vaccine for children at risk: Children who drop out of school are more vulnerable to HIV infection, are more likely to engage in early sexual activity with larger numbers of partners, and are more apt to use alcohol earlier than children who continue with their education (Save the Children UK 2001a). The single most certain step that any government can take to counteract HIV among the young is to increase the provision of education and to ensure young people remain in education programmes. Ensuring that every child gets into school, stays in school for a minimum number of years and has some worthwhile learning and skills at the end is critical, especially for girls (Coome and Kelly 2001; Vandemoortele 2001). ‘Education ministries should bend every effort to implement [EFA] strategy. Finance ministries should ensure that the resources are made available. The outcome will be a society with a lower incidence of HIV/AIDS, less poverty, greater female empowerment, and a human resource base from which the skills lost to HIV/AIDS can be replenished.’ (Kelly 2001a, p. 13)

Learning what works – monitoring and evaluation: None of the high-prevalence countries encompassed by this study has carried out an objective evaluation of life skills content, implementation and outcomes. Evidence from many sources makes it clear that, unless life orientation curricula are being taught in all schools, to all learners, before children become sexually active, by teachers who have been adequately prepared, with suitable resource materials, and within the context of the local culture and community, a great deal of money will be wasted.
If governments are not in a position to monitor the work of schools in this regard, the work must be contracted out to partner institutions or policy units and the results fed back into the system as a matter of priority.

Providing basic social support

Schools cannot meet all the material, intellectual, emotional and social needs of children who are distressed. Clearly HIV-affected children are not the only ones in dire circumstances. But governments can concentrate on keeping disadvantaged and challenged children in school or other suitable learning programmes and creating acceptably healthy, secure and compassionate learning environments for them (Morrell et al. 2001; Hepburn 2001; Williamson 2000a). Schools are already overloaded, but there are things that should be fundamental to every learning environment.

i) They must provide a healthy environment for learners and educators with adequate sanitation and nutrition (Coombe 2001c).

ii) They must be safe places, where there is zero tolerance for sexual abuse, harassment or abrogation of civil or human rights of any kind.

iii) They must be able to move beyond conventional teaching programmes and provide life and survival skills to children at relatively early ages. Educators must be able to identify children in trauma, handle them sensitively, provide basic counselling, and then know when to hand over to health, social services, home-based care or the police.

iv) They must all have a youth peer health team, trained by social and health workers, professionally skilled in medical knowledge, communication techniques, counselling and prevention.

v) They must have ways of referring learners in confidence to accessible voluntary testing and counselling sites, and must make informed decisions about condom provision, accessibility and guidance on use.

vi) They must work vigorously with community authorities, parents, NGOs and FBOs (South Africa Department of Health 2001).

vii) In high-risk areas, those with large numbers of HIV-affected learners should consider appointing specialist counsellors or social workers.

viii) Every learning institution must have a rolling HIV response plan, developed by staff, in consultation with students and parents, and the resources to implement it.

A common reason that HIV-affected children drop out of school, or perform poorly, is lack of material resources to meet basic needs. If short-term crises can
be avoided or managed, many orphans and other vulnerable children would be able to continue successfully with their schooling (South Africa Department of Health 2001). In Botswana, teachers and schools have developed a range of responses to vulnerable children’s needs, including recognition and referral of such children for grants and other support, providing supplies, monitoring orphan well-being, interacting with households and home-based care teams to reduce stress on children, helping with psychological needs and behaviour disturbance, and developing school HIV plans. Botswana already has an established culture of schooling and high female enrolments. There is less reliance on child labour for subsistence tasks, and relatively good prospects of work after completion of school. Government may have reduced the potential adverse effects of orphaning on learners by creating three complementary support programmes that together seem to keep many children in school, and help them perform adequately. The package is not a technically difficult one and includes school feeding, home-based care and orphan registration and subsidy (Abt Associates 2001).

Although some countries, such as Malawi, Uganda and United Republic of Tanzania, waive fees at primary level, Botswana is the only country in Africa where subsidies have been tried. Subbarao et al. (2001) make a strong argument for such subsidies, principally because they can easily be monitored, can reduce some of the financial burden on carers, and in the long term provide pupils with marketable skills.

**Teachers without support – meeting their needs:** Many teachers perceive that the system does not care about them. Their morale is low, not only because they are poorly paid, but also because too often the system is unresponsive to their needs and concerns. There are fundamentals of support to which every teacher is entitled:

i) Adequate knowledge of the aetiology of HIV, starting with a graphically illustrated book in an accessible language.

ii) Appropriate training and guidance in life skills curricula, with suitable learning materials.

iii) Access to counselling and confidential testing.

iv) In addition, heads of schools and teacher training institutes should have training in the management of HIV-related crises, especially in high-prevalence areas. While all pre-service teacher education programmes should make provision for basic tutoring on HIV issues, selected teachers, perhaps chosen by the pupils in consultation with the school head and governing body or parent–teacher association, should have further training in care and counselling techniques.

v) Wherever possible, educators in high-prevalence countries should have access to antiretroviral therapy. This is not only a cost-effective and humane response, but also is perhaps the only way to sustain the teaching service.
Sustaining provision of educational services

Impact assessments are necessary to identify the ramifications of HIV for the service. Botswana, Namibia, South Africa and Zimbabwe are assessing the impact of HIV on education in order to understand the impact of HIV on society and human resource development, as well as its internal impact on employees (education supply) and external impacts, focusing on learners and demographic shifts (education demand). Impact assessments provide the basis for understanding the social, economic, labour and planning implications of the pandemic for the sector, and to plan appropriate responses (South Africa Department of Education 2000a).

Projections of levels of HIV infections and illness and death among learners and educators are based on various prediction models, observations and interviews with key informants in the education sector. Also important for projections are data and information collected from development, finance, planning and medical aid schemes, group discussions with education managers, customized projections of learners and educators, field visits to education districts and reviews of relevant documents, policies and regulations (Abt Associates 2001; World Bank 2000a; South Africa Department of Education 2001b; impact assessments ongoing in Namibia and Zimbabwe).

It is no use undertaking impact assessments, however, if there is no planning and management capacity to respond to and implement their recommendations. Ultimately, by combining analysis with action, it should be possible to provide for:

i) Enough teachers to replace those leaving the service, especially those with scarce skills in university departments, teacher education, maths, science and technology.

ii) Supply teachers to cover for those regularly ill and absent.

iii) Enough new teachers to keep expansion and quality up.

iv) INSET support for those coping with trauma in the classroom.

v) Replacement of management skills lost to the system.

Protecting quality – responding to complex learning needs: Providing appropriate education of quality for orphans and other children at risk requires education systems to be increasingly flexible. For many systems, it will mean pressure to shift from the current generic focus on formal provision, to alternative learning modes, including lifelong learning strategies, adult education and literacy, a new ‘nonformal education’ paradigm (UNICEF and USAID 2000).

Curriculum adjustment – greater practicality: School curricula do not generally respond to the needs of learners affected by loss, or of those for whom immediate employment and income-generation possibilities are urgent necessities.
It might be difficult to provide vocational training but it should be possible to orient the curriculum towards the practical.

**Delivery system adjustment – greater flexibility:** If broad principles are established for the timetable, daily schedules, and even the education and training calendar, schools, colleges and communities could be allowed to regulate them in response to local requirements. To some extent this has been achieved in southern Africa, where such schools commonly charge no fees, require no uniforms, provide almost all educational materials and use teachers from within or close to the community, often on a voluntary basis and with little training (UNICEF and USAID 2000). Similarly, the Rajasthan Shiksha Karmi Project in India harnesses the energies of ‘barefoot teachers’ for children in remote rural areas where primary schools are either non-existent or dysfunctional (Swedish International Development Cooperation Agency 2001).

While the positive aspects of this development are the deep sense of community ownership and involvement, the danger is that such schools might become second-rate, catering for the poorest, or that the state might feel itself absolved of responsibility (Coombe and Kelly 2001). Other alternative responses include the use of interactive radio (Ghana Community Broadcasting Services 2001; USAID 2000), and the appointment of itinerant teachers who go out from a central school to animate and supervise tutors engaged by community groups. There is a growing sense in some communities that schools must be seen as comprehensive, community-based organizations where teachers are joined by those with a traditional role in society (leaders, healers, birth attendants, craftspersons) in collectively educating children (UNICEF and USAID 2000).

**Adjusting for teacher loss – alternative learning:** The simple solution of expanding teacher training capacity will not solve the problem of teacher attrition, and institutions may well be left short of teachers, lecturers and trainers. Alternative measures include a more systematic and extensive use of multigrade teaching (provided this is backed up by the resources, training and supervision it requires); greater reliance on educational broadcasting; more use of community members for supervisory responsibilities and for actual teaching in areas where they have some expertise; greater use of untrained (or ‘para’) teachers with a system in place for their ongoing training on the job; transferring certain curriculum topics or areas to co-curricular activities that would be managed by senior students; and more extensive provision for peer education (with some teacher supervision and monitoring). Children would have greater continuity of instructional and emotional support if younger children were to be linked with same-sex older children for tutoring, support and protection. They might be provided with instructional materials for out-of-school learning when necessary, or given help with individualized learning through sequenced learning materials for individual or group use, in or out of school (Harris and Schubert 2000).
Community backup – harnessing and supporting local resources: Community participation must be central to the response to AIDS. For education to combat HIV and manage its impacts, it must also be proactive in establishing linkages with the communities being served. Education authorities and institutions must constantly explore with communities how best they can be of service to one another. In Zambia, one objective of the education sector HIV strategic plan is for all schools and colleges to participate in home-based care and other responses to HIV-related community needs (Coombe and Kelly 2001; Zambia Ministry of Education 2001). Likewise in Botswana, close links are emerging between learning institutions, local NGOs and FBOs, and social and health workers (Abt Associates 2001). In Thailand, the Sanga Metta project, with support from local and international agencies, supports a shift in the focus of work of some Buddhist monks and temples in the direction of social responsibility for those suffering from HIV and AIDS, including orphans who become novices or are given education support. The programme is being extended in the region through UNICEF’s Buddhist Leadership Initiative (UNICEF East Asia and Pacific 2001b). The 2001–2002 plan of action of the South African Department of Education (South Africa Department of Education 2001c) includes provision for the establishment of 27 multi-purpose education and training centres linked to community development. They are particularly designed to assist with victim empowerment, cooperate with local programmes supporting victims of sexual violence and rehabilitation of school offenders, and ‘make schools centres of community life through innovations in infrastructure provisioning’. (South Africa Department of Education 2001c).

Women power – creating a safe environment: Possibilities for harnessing the energy of women in, around and on behalf of the school need to be elaborated. Mothers in Uganda are known to have mobilized in informal ways to save their daughters from death from HIV-related illnesses, and there is evidence that this is happening in South Africa. In Bangladesh, mothers teach their children in community schools; in Ghana, they make sure their children have access to potable water and food at school; while in Dominica, mothers become community teachers for five years before undertaking ‘initial’ teacher training. Mothers everywhere are likely to be the principal and most reliable guardians of their daughters’ well-being, but more needs to be done to mobilize them in the educational sector within their community.

Anecdotal evidence suggests that female teachers and principals are the ones who commonly deal with learners traumatized by conflict, poverty, loss and insecurity. There need to be more female teachers trained to help children who have complex emotional and learning needs and more female officials in positions of authority at school, district and higher levels. The idea of greater numbers of female principals, district officials, inspectors and senior executives is not new. Like much else about HIV and AIDS, what must be done is known. It is now a question of putting it into effect.
The challenges for countries with low HIV prevalence

Low infection rates in the early stages of an epidemic mean there are few motives for assigning resources to education sector action on HIV. The pandemic’s impact on education in low-prevalence countries will take years to determine because of the invisibility of the relatively low proportions of learners and educators affected. So, although one in nine of all those HIV infected lives in India, together they constitute less than 5 per cent of the total population, and a very small proportion indeed of the education community itself.

Prevention efforts need to focus on stemming the advance of the disease in Asia. This is particularly critical where patterns of transmission indicate stark similarities with the outbreak of the African pandemic, including high infection rates among truck drivers and increasing rates among pregnant women and transmission to their children (UNICEF 1999). Behaviour change through prevention interventions for targeted at-risk populations is currently thought to be the cheapest and most cost-effective way to maintain low HIV prevalence (UNAIDS/FHI 2001).

Young people are deemed to be a critical target population in low-prevalence settings if a society resistant to HIV is to be built in future. Most adolescents do not have settled sexual habits and patterns and their behaviours are easier to change if prevention efforts reach them before they enter risk zones. They are accessible in large numbers in existing institutions – schools and youth organizations – at relatively low cost, and they have proved to be a powerful force in their own right as active resources for prevention.

Committed and informed leadership

Strong leadership is indispensable (Botswana UNDP 2000, p. 49). There is general consensus, based on evidence from Botswana, Thailand, Uganda and elsewhere (UNICEF and USAID 2000), that effective action takes place when politicians, senior education department officials and senior international agency staff are ‘committed’, are convinced that disaster is around the corner and that their very systems are being steadily undermined. Politicians and officials need to be not just dedicated, but knowledgeable (Larson and Narain 2001, pp. 32–33). Education ministries need to work with partners inside and outside government in a holistic sector-wide approach that harnesses available resources in cooperative arrangements characterized by trust (Inter-Agency Working Group 2001; Larson and Narain 2001). Success will only come where local communities are empowered to take action on HIV themselves (Larson and Narain 2001; Save the Children UK 2001b). Governments must work in support of communities, and national management strategies, especially in the social sectors, must reflect this balance (Inter-Agency Working Group 2001). This will involve helping NGOs develop a diverse range of skills and resources (Khmer HIV/AIDS NGO Alliance 2001). Khana, in Cambodia, is working to
strengthen NGO capacity and strategic alliances among NGOs and public sector stakeholders (Khana 2000). The International HIV/AIDS Alliance is also dedicated to supporting community action on HIV in low- and middle-income countries, principally by assisting community groups to improve the quality of their work (International HIV/AIDS Alliance 2001; World Bank 2000b).

**Research, information sharing and analysis**

**Setting the research agenda:** There is as yet no set of research principles; HIV and AIDS research should be systematic and driven by demand, rather than by the preference of individual academics, officials and agency staff; it should be prioritized and part of a coherent and comprehensive education research agenda, linked to education planning and reform; it should also be networked, based on a set of common understandings and definitions, and focused on potential leverage points for change within schools, institutions, systems, procedures and administrations. Furthermore, there are as yet few research partners (within post-secondary institutions, policy units, government departments and the private sector) or resources allocated to non-curriculum HIV and education issues.13

**Collecting and sharing information:** More information is needed in order to establish a coherent set of qualitative and quantitative data. It should also be possible to identify a set of benchmarks and crisis indicators – alarm bells that indicate trouble – that can be monitored over time. Such data needs to be complemented by anecdotal evidence, observation and lessons from experience collected from practitioners and others, systematically and regularly (Harris and Schubert 2000; Botswana Ministry of Education 2000; Kelly 2001b; personal communications). Much more information specific to education is needed on prevalence, achievement, costs, education and training requirements and the psychosocial needs of affected learners.

**Using information:** Even more important, information must be analysed and shared if it is to contribute to understanding of how the pandemic threatens the education sector. IIEP’s programme of information sharing, action research and capacity building seeks to disseminate information about new studies, interventions, promising practices, tools and programmes and to provide planners and policymakers with advice on study design (Association for the Development of Education in Africa 2001).

**Management appropriate to crisis:** Education systems, even in high-prevalence countries like Botswana and South Africa, may not yet have had to deal with large-scale disruption except in small pockets, but eventually the systems are likely to be put under unmanageable pressure. The capacity of the sector bureaucracy to respond will therefore have to be considerably improved (Crouch 2001a). Management of the HIV crisis will clearly not be possible, given the present capacity, in many bureaucracies where there are still not enough adequately mandated, full-time, HIV-focused planners, strategists, managers or evaluators. Fighting
the pandemic is clearly not a part-time assignment for individuals dotted around
government or agency bureaucracies, but a full-time assignment until such time as
the situation stabilizes. It is also clear that ministries and agencies cannot simply
continue to react to the crisis, but must anticipate its consequences, and be far more
proactive in harnessing resources to counteract it.

**Policy and strategic planning:** Complex working arrangements will need to be
coordinated within a framework of common understanding about the nature of the
pandemic and its potential impact on the sector. Policy that is determined in a con-
sultative way needs to be interpreted for educators and officials responsible for
implementing it in the form of guidelines and guidance notes, regulations and codes
of conduct, so that local, national and regional efforts are focused and purposeful.

**Resource allocations:** There has been some movement towards making funding
arrangements for HIV and education more efficient, more appropriate to the kind of
partnership arrangements envisaged here. But more is required by both ministries of
finance and by international agency partners. On both sides, structures and procedures
inhibit movement of funds to local programmes that could make a difference. The ar-
gument has been won that adequate provision for local and national **non-government**
partners must now be made through government or non-government funding mecha-
nisms. World Bank experience on social sector support, joint funding mechanisms
being designed by bilaterals for SWAp purposes, and the use of fundholders by agen-
cies all provide useful guidelines from which to learn and on which to act.

**Monitoring achievements:** Impact assessment researchers recognize the limita-
tions of relying on mathematical models, and recommend monitoring key indicators
that can be used to track the progress of the pandemic, including educator absenteeism,
deaths among staff, particularly teachers, school enrolment and dropout rates disag-
gregated by gender, and numbers of pupils orphaned by AIDS (Johnson 2000).

**Conclusion**

It is virtually impossible to generalize about good practice, as what works to break
the power of HIV in one place may not work in another, but radical, early human-
itarian interventions to tackle STIs, provide condoms, establish home-based care
and school feeding schemes and train peer health teams for all institutions can save
lives in the short term, while pilots are being tried, governments are mobilizing
and allocating resources, the capacity of NGOs is strengthened, planning kicks in
and behaviour change programmes start up.

Global experience suggests there are a number of longer-term generic tools that
can make a difference with regard to HIV and education, save lives and protect
education quality.

The first tool is honesty. It is essential to stop pretending that progress is being
made against HIV and AIDS. This is an overwhelming disaster and so far little has
been done to confront it effectively. It is absolutely essential to enhance crisis management capacity in and out of government.

Second, working together, making use of all available resources – and especially the skills of girls and women – is the best route to take. All poverty reduction programmes must factor HIV into their plans so that the pandemic can be addressed within the context of poverty that drives it. There are thousands of examples of good, very good and potentially good practices at community level, and although these are generally small-scale, ad hoc and underfunded, NGOs, CBOs and FBOs are making a difference in the lives of women and children. They provide support to teachers and heads as counsellors. They train children and teachers in peer counselling. They teach lessons of safer sex, work in communities to defuse violence, and care for the abused and violated. They are at the coalface. Their contribution is not just considerable, it is fundamental – however fragmented it may be. Strengthening education’s response now depends on how the programmes of non-government partners are integrated into the sector’s strategic planning and resource allocations, and whether or not they can be taken to scale.

While governments clearly have a role to play in coordinating and strengthening local responses, creating policy and establishing a regulatory framework and delivering health and social welfare services appropriate to community requirements, ultimately they must work in support of communities, and national management strategies must reflect this balance.

No one underestimates the difficulties. There are few models from which to learn and ministries of education have struggled for years to decentralize decision-making and executive responsibility.

Third, it is only by monitoring the success of interventions, and evaluating whether they can be replicated or generalized, that governments and agencies can be held accountable for taking effective action, against agreed performance benchmarks wherever possible. There is as yet no clear perception that the potential of HIV and AIDS to create havoc for the education sector requires immediate intensive and extensive response. But that is what is required. The challenge of millions of children being orphaned by AIDS in several regions by 2010 may serve to inculcate a global sense of responsibility in both learners and educators.

HIV is, for many countries, the most significant issue in education today, and probably the biggest challenge to development. The need to confront the pandemic responsibly will require a fundamental re-think of development principles and procedures, and of the relationships between governments and their funding partners. HIV is rooted in poverty, and until poverty is reduced, little progress will be made in limiting its transmission or coping with its consequences. A development, rather than an HIV-specific, focus is essential now.
References and Bibliography


**Notes**

1. HIV affects all education subsectors, from early childhood development to colleges and universities and must therefore be tackled at all levels. The response should also include concern for out-of-school young people, and the creation of adult basic education, non-formal and distance education opportunities for children and young people disadvantaged by HIV. There is little evidence of critical analysis of the pandemic’s implications for these education subsectors, even in high-prevalence countries. The lack of strategic thinking about technical education, early childhood development and out-of-school programmes has been highlighted regularly with little effect.

2. ‘Projections for South Africa, for example, are based on the most recent statistics using the Metropolitan-Doyle model, first published in October 1990, to produce reliable estimates of the progress of HIV in South Africa. The model has been extensively used in Southern Africa by many sectors… and has performed well when used in practical applications at the sub-group and general population level. The model is continually reviewed in the light of new demographic and population statistics, [and] is able to consider various interventions including behavioural changes (increased condom usage, reduced numbers of partners, etc.) and medical interventions (improved treatment of STIs, vaccinations, treatment of HIV-positive and AIDS-sick individuals).’ (Moore and Kramer 1999, p. 14)

3. Crouch’s list of the assumptions that need to be factored into a relatively accurate teacher demand and supply projection are set out in table 7 of his paper.


5. Whether teachers have higher infection rates for these reasons, or because teachers are predominantly young women at high risk, is not clear.

6. The South African Medical Research Council reported late in 2000 that one half of all schoolgirls had been forced to have sex against their will, one third of them by teachers. ‘We were shocked by the finding that teachers are the major perpetrators of child rape, but no one experienced in education seems to be surprised.’ The Minister of Education reported subsequently to parliament that there were perhaps six to eight cases involving sexual abuse pending with the South African Council for Educators, and that in most cases the accused were still in the classroom (Coombe 2001b).

7. Generally defined as including the ability to distinguish between healthy lifestyles and risky behaviours (such as unprotected sex, substance abuse and violence); the development of a strong self-concept and skills to resist peer pressure; and an examination of the situation of women, gender equity and healthy family relationships.

8. Survey undertaken by staff of the University of Pretoria Faculty of Education (2001).

9. The 13 countries that reported are Angola, Botswana, Lesotho, Malawi, Mauritius, Mozambique, Namibia, Seychelles, Swaziland, South Africa, Tanzania, Zambia and Zimbabwe.


12. South Africa has done a partial review in KwaZulu-Natal province (Macintyre et al. 2000), and another partial review that has not been released by the Department of Education (Khulisa 2000).

13. Personal communication from Cicil Hartell, University of Pretoria Faculty of Education; and from the Vice Chancellor, University of Botswana.
Chapter 10
The Impact of HIV on Child Health and the Health System

Giovanni Andrea Cornia, Mahesh Patel and Fabio Zagonari

Introduction
This chapter focuses on the impact the HIV epidemic has had on the health sector and the health status of children in 40 countries with medium to high HIV prevalence. With the rise in prevalence at antenatal clinics reaching 50 per cent (as in some areas of Botswana), and with adult prevalence of over 20 per cent in several parts of Africa, the health sector has been particularly hard hit. It now suffers from attrition of personnel, while at the same time it needs to perform at well above its pre-epidemic levels in order to control the spreading contagion and to care for those affected. In countries with adequate economic growth and low infection rates, increases in health budgets will often be sufficient to cope with the crisis. But in several highly indebted poor countries, where the health sector has been deteriorating since the 1980s, most markedly following the adoption of structural adjustment programmes, infection rates are high (Simms et al. 2000). In most of these countries, HIV has also caused a rapid increase in the demand for hospital-based treatment, which has led to weakening of health care at the primary level. How to control the negative effect of HIV, without weakening other essential interventions, is the main health sector challenge faced by the policymakers of many low- and middle-income countries.

The health sector response to the HIV pandemic initially focused on prevention of the contagion and treatment of opportunistic infections. In some middle-income countries, the response has gradually also included the treatment of HIV-affected newborns, mothers and – in some cases – adult males. However, in all countries, the public policy response to mitigation of the health impact of HIV on children and their families has been limited. Families have had to cope with the devastating effects of HIV – poor health, impoverishment and social marginalization – themselves. Thus, the optimal policy for the health sector in HIV-affected countries is still the subject of an evolving debate.
To try to answer these questions, the second section assesses the impact of the HIV pandemic on the functioning of the health sector, the main aim being to understand the changes in actual demand for, and supply of, public and private health services for HIV- and non-HIV-related ailments. The third section reviews the impact of AIDS on child mortality and the availability of health services for children. Unlike in the educational sector, where HIV appears to have had a so far limited impact on enrolments (see chapter 9), there is evidence that AIDS has had a devastating impact on child mortality in many countries. The health policies and programmes introduced to combat the pandemic and the comparatively neglected issue of antiretroviral drug treatment are discussed. Then the measures that have been, or could realistically be, introduced to sustain health care provision for children and mothers in AIDS-affected countries are examined.

Framework of analysis

Short-term impact of HIV and AIDS: the demand for health services

The spread of HIV has massively increased demands on the health sector: as the HIV virus weakens people’s immune systems, it increases their susceptibility to a host of other diseases, such as TB and meningitis. In sub-Saharan Africa, up to 50 per cent of people with HIV develop TB.

Whether or not the surge in latent need for health care to deal with these opportunistic infections is transformed into an increase in effective demand for such care depends on a number of factors. To start with, it depends on ‘prices’, including the price of the health care itself and the price of other essential items, such as food and funeral services. The second main factor is the change in household income of people affected by HIV, and the third is social stigma. It is likely that HIV increases demand for health care more than other diseases because it is considered to be more lethal (Nandakumar 2000). On the other hand, the social stigma of HIV has the opposite effect (see Muyinda et al. 1997 on Uganda). When a patient is unaware of his or her condition, the demand for health care also depends on the behaviour of the health care personnel. Gibney et al. (1999) show that physicians in Zimbabwe frequently choose not to test patients for HIV, fearing that they would be traumatized, and even commit suicide.

The spread of HIV may give rise to a substitution, or ‘crowding out’, effect, by which the demand for health care for non-HIV-related diseases declines due to the increase in the burden of disease, the high cost of HIV treatment or an increase in user fees. Conversely, the HIV epidemic can lead to a complementary, or ‘crowding in’, effect due to a reduction in the cost of care for non-HIV-related diseases, if, for example, a patient takes advantage of a health care visit for HIV problems to seek treatment of other ailments. The evidence reviewed below suggests that in high-prevalence and low-income countries, the ‘crowding out’ effect dominates.
The most relevant changes that have taken place in this area over the last decade can be summarized as follows.

(i) Overall demand for health care has increased sharply due to HIV. Worldwide, AIDS is now the fourth most important cause of death, ahead of TB, malaria and diarrhoeal diseases.

For the year 1999–2000, AIDS was by far the main cause of death in the ‘high-prevalence countries’ of sub-Saharan Africa (see table 1), despite possible underreporting and underestimation of its prevalence due to classification problems. In Zambia, about 70 per cent of the 40,000 TB cases recorded annually are related to AIDS (Silungwe 2000). Yet, AIDS is not the main cause of death in all African countries. In 2000 in Ghana, with an HIV prevalence of 3.6 per cent, malaria was the reason for 40 per cent of all outpatient visits, and all the TB, AIDS, measles and leprosy cases combined totalled only one fifth of the number of malaria cases. Moreover, malaria is the main cause of death among children under five years of age and accounts for 25 per cent of all deaths in that age group (Senaya 2001).

Table 1. Rank and percentage burden of disease for the first 10 causes of death in sub-Saharan Africa (2000)

<table>
<thead>
<tr>
<th>Rank</th>
<th>Disease</th>
<th>Percentage of deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>AIDS</td>
<td>20.6</td>
</tr>
<tr>
<td>2</td>
<td>Acute lower respiratory infections</td>
<td>10.3</td>
</tr>
<tr>
<td>3</td>
<td>Malaria</td>
<td>9.1</td>
</tr>
<tr>
<td>4</td>
<td>Diarrhoeal diseases</td>
<td>7.3</td>
</tr>
<tr>
<td>5</td>
<td>Perinatal conditions</td>
<td>5.9</td>
</tr>
<tr>
<td>6</td>
<td>Measles</td>
<td>4.9</td>
</tr>
<tr>
<td>7</td>
<td>Tuberculosis</td>
<td>3.4</td>
</tr>
<tr>
<td>8</td>
<td>Cerebrovascular disease</td>
<td>3.2</td>
</tr>
<tr>
<td>9</td>
<td>Ischaemic heart disease</td>
<td>3.0</td>
</tr>
<tr>
<td>10</td>
<td>Maternal conditions</td>
<td>2.4</td>
</tr>
</tbody>
</table>

Source: Elaboration of data from WHO 2000.

The main causes of morbidity and mortality among children tend to be different from adults, particularly in low-prevalence countries. Young children generally only contract HIV at birth or during breastfeeding, and it is other types of ailments such as measles, diarrhoea and malaria that affect most children and are still the main cause of child deaths. Yet, in countries with a comparatively low level of U5MR before the onset of AIDS, and a large increase in HIV prevalence over the last 10–15 years, AIDS has become the most important cause of death among children.
Even in medium-prevalence countries – such as Thailand – the relative importance of AIDS as a cause of death remains high. Tangcharoensathien et al. (2001) show, for instance, that during the period 1993–1997, AIDS was the sixth cause of death, despite the under-reporting of such deaths outside hospitals. In many cases, AIDS deaths are attributed to diseases such as malaria, TB, respiratory infections and fever. If classification bias is taken into account, AIDS becomes one of the top three causes of death in Thailand too.

In low-prevalence countries, HIV still remains a serious public health problem for certain population subgroups. Saavedra (2000) shows that in 1997 in Mexico (1999 prevalence of 0.3 per cent), AIDS represented only the 15th cause of death among the general population, but the ninth among the population of working age. In specific subpopulations, the problem is more acute. Avila-Figueroa (1999) suggests that AIDS is the first cause of death in men between 25 and 44 years old in Brazil, Mexico and Venezuela.

The impact of HIV on the health sector can also be gauged by examining service utilization data. The demand for HIV-related health care services increased in relative terms as a share of the total demand for health care in practically all countries with HIV prevalence above 2 per cent.

Information on bed usage by patients with HIV-related illness is available from major hospitals in a number of countries (WHO 2001a). For several hard-hit countries, loss of hospital capacity for non-HIV-related patients could be over 50 per cent, as indicated by the data in table 2 and the literature surveyed below.

**Table 2. Percentage of hospital beds occupied by HIV-positive patients in selected developing countries with medium to high prevalence (circa 1995)**

<table>
<thead>
<tr>
<th>City</th>
<th>Hospital</th>
<th>% beds occupied by HIV-positive patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chiang Mai, Thailand</td>
<td>Provincial</td>
<td>50</td>
</tr>
<tr>
<td>Kinshasa, D.R. Congo</td>
<td>Mana Yemo</td>
<td>50</td>
</tr>
<tr>
<td>Kigali, Rwanda</td>
<td>Central</td>
<td>60</td>
</tr>
<tr>
<td>Bujumbura, Burundi</td>
<td>Prince Regent</td>
<td>70</td>
</tr>
<tr>
<td>Nairobi, Kenya</td>
<td>Kenyatta National</td>
<td>39</td>
</tr>
<tr>
<td>Kampala, Uganda</td>
<td>Mulago</td>
<td>56</td>
</tr>
</tbody>
</table>


Already in 1988–1993, the share of bed occupancy by patients who were HIV-positive and with HIV-related illness in selected urban hospitals in Abidjan, Kampala, Kigali, Kinshasa, Lusaka and two Zambian hospitals was close to 60–70 per cent (Buvé 1997). In Zimbabwe, bed occupancy for AIDS rose tenfold during the 1990s. In Zambia, hospital bed occupancy for AIDS is expected to swell from about 6 per cent
to 43 per cent between 1990 and 2005 (Mpundu 2000). In Botswana, at least 60 per cent of hospital beds are occupied by patients with HIV-related disorders (Makhema 2000). Similar results are reported by Colvin et al. (2001) for South Africa and Tembo et al. (1994) for Uganda. Thus, in high-prevalence countries, HIV clearly has a major effect on the supply of non-HIV-related health services.

In high-prevalence countries, data on medical consultations tell a similar story. In Rwanda (prevalence of 11.2 per cent in 1999), a study of some 350 HIV-positive people shows that on average each had 10.9 annual outpatient visits, as opposed to a meagre 0.3 for the general population (Nandakumar et al. 2000). The study also reveals that the increased demand for outpatient services was characterized by considerable inequity of access and income. Patients in urban areas utilized services 10 times more than those in rural areas (due to easier access and higher incomes), with those in the top quintile doing so twice as often as those in the bottom quintile, and the married patients 40 per cent more than the single or widowed ones. In addition, the study indicates that only 30 per cent of the sample patients were able to pay the full cost of the visits themselves; the majority had to resort to assistance, selling assets or borrowing money from a bank or relatives.

Even in low- to medium-prevalence countries, there is local evidence of such ‘crowding out’ effect. In the Maechan hospital in Thailand, the share of the total budget spent on HIV rose from 20 per cent to 40 per cent between 1995 and 1997, while that of cases treated for HIV rose from 3.7 per cent to 7.1 per cent (Tangcharoensathien et al. 2001).

(ii) There is evidence that in several countries the demand for, and effective treatment of, HIV-related diseases has crowded out that for non-HIV-related diseases. The above Thai study shows that HIV-related costs rose at the expense of the non-HIV health budget. A study on Zambia (Mpundu 2000) describes a similar trend – a trend that also entailed a greater concentration of health resources on tertiary care and the slashing of precious resources formerly assigned to district health centres. In some districts in Kenya, the high hospital bed occupancy by patients with HIV-related illness prevents access to care by people with other conditions (Rachier 1999). One of the reasons for the higher allocation to HIV is that it is far more expensive to treat. A study on Zimbabwe (Hansen et al. 1998) shows that, due to longer average length of stay in hospital and higher daily costs (medication, laboratory tests and X-rays), hospital care was twice as expensive for patients with HIV-related illness as for non-HIV-related.

**Short-term impact of HIV and AIDS: the supply of health services**

HIV and AIDS affect the various tiers of health care systems to a different extent. National health care systems usually provide services (often for a fee to supplement scarce public funds and external donations) through a three-tiered structure, such as outlined below:
Village-based **public health centres**, staffed by one or two low-paid public health workers who receive limited training on the screening and treatment of the most common ailments and support for the implementation of public health campaigns. They refer cases they are unable to treat to higher levels of care.

The city-based **health centres/district hospital**, staffed by trained nurses and, in some cases, general practitioners. While they provide mainly outpatient care, they can often also provide inpatient care in small wards. There is generally a fee for these services, though the preventive component ought to be free. Fees for services tend to be higher in these institutions than at the primary level, yet evidence shows that public health centres are utilized much less than the local or central hospital infrastructure.

**General and specialized hospitals**, located in the provincial and national capitals. They are staffed by nurses, general practitioners and specialists and have specialized wards (e.g. for infectious diseases). They provide outpatient care and a range of curative, mostly inpatient, care services. The patients, except for those who are public employees covered by health insurance, pay for hospital-based care. User fees are designed to discourage people from seeking care for simple diseases in such hospitals.

**The private health care sector**. This is generally staffed by doctors who often hold dual employment, in both the public and private sectors (Chawla 1997). It includes traditional healers as well as modern units that provide good but expensive care to high-income people. In middle-income countries, the private sector caters to patients with health insurance and the staff of large enterprises (Kikumbih et al. 1997).

In low-income countries, the public sector dominates in terms of numbers of patients treated (over 90 per cent of the total) as well as of funds expended. In Rwanda, 68 per cent of total health expenditure is in the public sector, 9 per cent is allocated to NGOs and the rest to the private sector (Schneider 2001). In Thailand, of the total health expenditure in 1994, 36 per cent was spent on purchasing care from public providers, 32 per cent from private providers, 6 per cent on administration and 9 per cent on all other public health programmes. Roughly half the total financing originated from the public budget and the rest from private sources.

Three types of constraints on the ability of the health sector to supply services will be considered: a reduction, or slower growth, in the supply of labour due to greater mortality/morbidity among health care providers, including their declining morale and/or efficiency; changes in the demand for health services; and constraints on recurrent budgets.

High HIV prevalence among health workers is one of the main reasons for decline of health services. Epidemiological surveys from sub-Saharan Africa have shown that HIV incidence has been disproportionately high among people with
high human capital such as doctors, nurses and hospital administrators who are likely to be part of the ‘mobile population’ posted away from their families and thus exposed to a high risk of contagion. In Zambia, mortality among nurses rose from 2/1,000 in 1980–1985 to 26.7/1,000 in 1989–1991, while absenteeism reached 16 per cent (Buvé et al. 1994). Overall, the World Bank (1999a) estimated that a country with a stable 5 per cent prevalence could expect that between 0.5 per cent and 1 per cent of its health care providers would die from HIV-related diseases annually. A country with a 30 per cent prevalence would lose 3–7 per cent of its health workers to the epidemic each year (ibid.).

The 60 countries most affected by the epidemic employ about 2.5 million physicians, 2.2 million nurses and 100,000 midwives, totalling nearly 5 million (WHO 2001b). Many of these are HIV-positive, but the impact on the functioning of the health sector is more dependent on the number of AIDS cases and deaths than on HIV infections, which remain latent for some years. As the mortality rate is normally about 10 per cent of the prevalence, there would be some 5,000 deaths annually among the approximately 5 million health sector staff. But these figures conceal wide national variations. While for sub-Saharan Africa overall an average 8 per cent of staff are infected and mortality could be about 1 per cent, in countries such as Botswana, Lesotho, Namibia, South Africa, Zambia and Zimbabwe, the adult prevalence is between 20 per cent and 30 per cent, so up to 25 per cent of the health staff may be infected and 3 per cent already dead.

In the short term, a loss of 3 per cent in the health sector is not catastrophic, but the medium-term implications are more serious. A national infection rate of around 30 per cent implies that up to one third of health sector staff may need to be replaced over the next six to seven years. This means that the intake of medical and nursing schools would need to approximately double. This has been the case in Uganda, where the number of nurses and doctors rose from about 2,200 and 1,200 in 1990 to 6,700 and 4,500 respectively in 2000 (chapter 2). However, such increases in the number of health staff are not taking place elsewhere, and some countries may face a staff deficit of up to one third of current levels.

A study on Zambia (Foster 1993) attributed an increase in the mortality of nurses between 1986–1988 and 1989–1991 to AIDS due to occupational exposure. Another study from South Africa (Gounden and Moodley 2000) found that 13 per cent of the staff reported injuries with HIV-positive patients. Health personnel also suffer from ‘occupational burnout’ due to stress caused by the epidemic.

The quantity/quality of health services may also have eroded due to greater absenteeism, low morale and refusal of staff to be transferred to high-prevalence regions. Rising morbidity/absenteeism among nurses and doctors has serious implications for staffing planning and the ability of the health system to cope. In countries with high prevalence, there has for many years been a shortage of nurses and even more so of doctors, particularly in remote and rural areas. The decline in
salaries and the perceived greater risk of dealing with HIV-positive patients has led to demands for ‘special AIDS allowances’, which – where these have not been met – have led to an exodus to the private sector or to countries with higher salaries, such as South Africa and the United Kingdom.

The demand for HIV-related services has been directed mainly to the intermediate and upper tiers of the health system, not the primary level. HIV testing and counselling, and palliative care for TB and other opportunistic infections, as well as treatment with antiretrovirals, tends to be carried out at higher levels of care, despite the fact that their unit costs are higher than at lower level.

While the primary and secondary levels of health care provision may have been less affected by the new demand for HIV care, they may have suffered because of the drainage of resources towards higher levels of care. With broadly constant health budgets, as much as 50 per cent of the funds may have gone to hospital care for patients with HIV-related illness, causing a drop in resources assigned to the primary and secondary levels of care. In Thailand, during the recent economic downturn and budgetary stringency, district hospitals in the northern provinces had to cap drug expenditure on opportunistic infections. Moreover, district hospitals referred patients to upper levels of care (Pothisiri et al. 1998).

AIDS-induced changes in public and private recurrent expenditure on health

Total health expenditure as a percentage of GDP in low- and middle-income countries is not fundamentally different from that of some industrialized countries (table 3). In 1998, with a share of 4–6 per cent of GDP allocated to public and private health expenditure, Rwanda, Ghana and Zimbabwe were in a similar situation to that of low health expenditure OECD countries (UNAIDS 2000a).

Table 3. Total public and private health expenditures as a percentage of GDP in late 1990s

<table>
<thead>
<tr>
<th>Country</th>
<th>Total health expenditure</th>
<th>Public health expenditure*</th>
<th>Private health expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ghana</td>
<td>4.7</td>
<td>1.8</td>
<td>2.9</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>6.4</td>
<td>3.1</td>
<td>3.3</td>
</tr>
<tr>
<td>Rwanda</td>
<td>5.0</td>
<td>3.0*</td>
<td>2.0</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>6.4</td>
<td>5.4</td>
<td>1.0</td>
</tr>
</tbody>
</table>

Note: * Includes also international assistance; in Rwanda, 2.5 per cent of the 3 per cent was foreign aid.

However, while the percentages may not differ greatly, the actual sums involved do. In 40 HIPCs, health expenditures average $10 per capita, well below the $60 minimum expenditure suggested by WHO and 20 per cent to 40 per cent lower
than the cost of the World Bank basic package of health services. To put this $10 expenditure in context, in poor economies, the health sector expenditure required for prevention alone has been estimated at $5 per capita (Patel 2000). Current expenditure on prevention is only about $0.20 per capita, of which government expenditures amount to $0.02. Care services are similarly constrained.

The most common response has been to require patients to cover most of the cost of HIV care, thus limiting treatment to those who can afford it. In addition, while in industrialized countries public expenditure accounts for 80–90 per cent of total health expenditure, in low- and middle-income countries it is between 40 per cent and 50 per cent (including aid). In Uganda, the Government spends only $4 per capita annually on health, while per capita health spending from both public and private sources rose from $8 in 1994–1995 to $10.79 in 1997–1998, while foreign aid declined from $1.28 in 1994–1995 to $1.09 in 1997–1998 (table 4). At the local level in Thailand, Tangcharoensathient et al. (2001) report that in 1997 in Chiangrai province, the householders’ share of HIV-related health expenditure was 43 per cent, and in Phayao province it was as high as 65 per cent. Mexico and Brazil show two extreme situations. In Mexico, subsidies cover only 26 per cent of the cost of HIV care, but 76 per cent of the costs for non-HIV treatments. In Brazil, antiretroviral therapy is free, whereas only 33 per cent of other health services are subsidized.

Table 4. Recurrent per capita health expenditure in $, total and by source, Uganda, 1994–1998

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Total recurrent expenditure</td>
<td>11.22</td>
<td>12.19</td>
<td>13.84</td>
<td>14.27</td>
<td>3.05</td>
</tr>
<tr>
<td>– Private</td>
<td>8.00</td>
<td>8.82</td>
<td>9.75</td>
<td>10.79</td>
<td>2.79</td>
</tr>
<tr>
<td>– Public</td>
<td>1.94</td>
<td>2.05</td>
<td>2.91</td>
<td>2.38</td>
<td>0.44</td>
</tr>
<tr>
<td>– Foreign aid</td>
<td>1.28</td>
<td>1.32</td>
<td>1.18</td>
<td>1.09</td>
<td>-0.19</td>
</tr>
</tbody>
</table>

Source: Elaboration on Mirembe et al. 1998.

What has been the impact of HIV on health expenditure? In low-income countries, despite its depressive effect on family incomes, the epidemics triggered an increase in private health spending that led to a reduction in household consumption of basic items. In contrast – with a few exceptions, such as Uganda – public health expenditure stagnated owing to budgetary restrictions and, in some cases, to restrictive adjustment policies and mounting debt service obligations. On average, from 1990 to 1996, public health expenditure as a share of GDP stagnated at 1.1 per cent in low-income countries and rose moderately from 3.0 per cent in middle-income ones. This pattern of stable public, and rising private, health expenditure is well illustrated by table 4.
The changes in health spending were less dramatic in middle-income countries with health insurance and low prevalence. In these countries, the HIV epidemic has often been accompanied by an increase in public health expenditure and stagnant private health expenditure. In Brazil, the federal expenditure on antiretroviral drugs rose from $34 million in 1996 to $224 million in 1997 and to $332 million in 2000 (Sarna 2001). In Thailand, the HIV budget expanded from Baht 6 million (in constant 1995 prices) in 1988 to 218 million in 1991, then to 2,066 million in 1996, only to decline in the wake of the Asian crisis to around 1,200 million for the period 1998–2000 (Tangcharoensathien et al. 2001, and chapter 5).

The long-term impact of HIV and AIDS on the health status of children

Child mortality trends in the AIDS era

Most of the recent debate on the mortality impact of HIV has focused on changes in adult death rates and neglected the impact on the elderly, infants and young children. In fact, the impact of HIV on child mortality remains controversial. One view is that, in countries with moderate adult prevalence, the impact is negligible. An examination of trends in services for children (vaccination, delivery care and oral rehydration therapy) for the last 20 years in 40 countries with adult HIV prevalence greater than 1 per cent, leads to the conclusions summarized in table 5. There are four main country groupings:

(i) **Countries with high adult HIV prevalence (>6.5 per cent), high pre-AIDS coverage of child health services and low pre-AIDS U5MR, showing a marked or moderate reversal of the trend towards lower U5MR.** Such reversal started in the late 1980s in countries with ‘mature epidemics’ such as Kenya, and from the early to mid-1990s in countries with ‘recent epidemics’ such as Botswana, South Africa, Zambia and Zimbabwe. The average extent of the reversal is 20–30 per cent; but in Botswana, U5MR declined from 84 to 58 per 1,000 between 1980 and 1990 and then jumped to 101 per 1,000 by 2000 – a 75 per cent rise in U5MR in a decade. In other words, HIV more than erased the gains in child mortality achieved in the 1980s.

In a second group of four countries with a high adult prevalence that had achieved a rapid expansion of child health services coverage during the 1980s and 1990s, the U5MR rise was less, 5–10 per cent, as any increase due to perinatal HIV transmission was in part offset by the decline in non-HIV-related child deaths.

(ii) **Three countries (Angola, the Democratic Republic of Congo and Liberia) with a moderate increase in U5MR.** The prevalence of HIV and paediatric AIDS mortality rose only moderately, but child health care coverage was so low, due to conflicts and social turmoil, that they had not previously managed to reduce child deaths from causes other than AIDS.
(iii) Countries with consistent downward trend of U5MR (11 cases) or slower than expected decline (7 cases). In countries such as Benin, Burkina Faso, the Dominican Republic and Ghana, with low pre-AIDS coverage of child health services and high pre-AIDS U5MR, the surge in AIDS-related child mortality was more than offset by a decline in child mortality due to expansion of immunization, maternity care and other interventions in the 1980s. This effect was less pronounced in the 1990s, as coverage levelled off. To a certain extent, these countries followed the trend of the first group and were able to benefit from the ‘basic health services dividend’.

(iv) A country able to maintain the U5MR downward trend. Thailand was able to control HIV prevalence through an effective prevention campaign and thus avoided a large rise in perinatal HIV cases, while at the same time sustaining coverage of the usual basic health services for children.

Table 5. Countries grouped according to changes in U5MR trends, increases in HIV infection rates and basic health services coverage

<table>
<thead>
<tr>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(ii) U5MR trend rises moderately</td>
<td>Benin, Gambia, Ghana, Guinea, Honduras, Mali, Madagascar, Panama, Niger, Nigeria*, Uganda*</td>
<td>(iii) U5MR falls more slowly than the trend</td>
<td>(iv) U5MR falls on trend</td>
</tr>
<tr>
<td>[U5MR trend rises rapidly Burundi, Cameroon, Cote d’Ivoire, Rwanda]</td>
<td>[U5MR falls on trend Ethiopia*, Mozambique*]</td>
<td>[U5MR falls on trend Lesotho*, Malawi*]</td>
<td>[U5MR trend rises rapidly Botswana, Congo, Kenya, South Africa, Swaziland, United Republic of Tanzania*, Zambia, Zimbabwe]</td>
</tr>
</tbody>
</table>

Source: Compilation by the authors, based on UNAIDS 2000a, US Bureau of Census, UNICEF and WHO. Note: *Indicates a trend that is apparently inconsistent, but might be due to lack of up-to-date surveys for accurate U5MR measurement.
Causal analysis of changes in child mortality in AIDS-affected countries

The four-way classification proposed in table 5 sheds some light on the factors explaining the child mortality changes during the last 20 years, but needs to be complemented by a more rigorous approach that takes into account all the factors, including HIV, that influence child mortality rates.

Impact of HIV on child mortality: HIV affects child mortality rates in three ways: First, infants born to an HIV-positive mother have a 30 per cent probability of being infected by the virus, contracting AIDS and dying within one or two years, although the impact of paediatric HIV can be offset by the treatment of the newborn with nevirapine or other programmes to prevent mother-to-child transmission. Second, child mortality due to infectious and waterborne diseases may increase over the short term if the increasing demand for palliative care and the care of opportunistic infections absorbs funds otherwise devoted to immunization, oral rehydration therapy and delivery care, as well as the capital expenditure on the maintenance and development of the health infrastructure. HIV could also affect U5MR because of the decline in the stock of doctors, nurses, paramedics and PHC workers due to an HIV-induced rise in mortality, attrition, out-migration and burnout among them and inadequate training of new staff. The weakening of the overall health care sector should also be demonstrated by an increase in child mortality due to infectious and waterborne diseases. Third, mortality among children may also increase because of the HIV-induced impoverishment of the family in which the child lives. Chapter 7 shows that average incomes drop by up to 50 per cent in families whose head died from HIV-related infections during the prior 18 months. This effect ought to be captured by a rise in U5MR due to malnutrition and other poverty-related diseases. Finally, it is worth noting that all these effects are exacerbated if the virus is of the HIV-2 type rather than the HIV-1 type.

Changes in the traditional determinants of U5MR: In countries with high pre-AIDS U5MRs, the upward shift in aggregate U5MR may have been more than compensated by changes in the ‘traditional determinants’ of child mortality, i.e. income per capita, income distribution, female education, access to fresh water supply and coverage of basic health services.

Between 1980 and 2000, income per capita stagnated in most AIDS-affected economies, and in a few it fell for several years. In those affected by large falls (e.g. Zambia), low-income groups and their children reduced food intake and thus became less resistant to infection. In contrast, acceptable growth was recorded in Burkina Faso, Ghana and Thailand (where U5MR fell on trend), as well as in Uganda (where it first stagnated and then fell) and Botswana (where it rose sharply from 1990). A worsening distribution of income (proxied by changes in the Gini coefficient) may have also contributed to the changes in U5MR in AIDS-affected countries. Here too, however, the limited information available suggests that this
is unlikely to be a key factor in explaining the changes in U5MR in the AIDS-affected countries. For instance, inequality rose in Kenya in the decade 1982–1992, while U5MR declined. This was also true of Thailand over the last two decades of the 20th century.

Meanwhile, female literacy – a key determinant of U5MR – changed slowly in most AIDS-affected countries and is therefore unlikely to explain much of the observed changes in U5MR. Finally, the coverage of fresh water supply and of highly effective pro-child interventions such as maternity care, child immunization, oral rehydration therapy, promotion of breastfeeding and micronutrient and food supplementation expanded rapidly during this period. However, in several countries, progress in these areas slowed down or was reversed in the late 1990s, either as result of the ‘crowding out’ of primary health care by the increasing demand for HIV care or because of the fiscal crisis affecting many AIDS-affected countries.

**New confounding factors:** U5MR has also been affected by a surge in the number of armed conflicts, humanitarian emergencies and natural disasters that have not spared the AIDS-affected countries (table 6). Major food shortages, often reaching famine proportions, have been common in sub-Saharan Africa, and the number of fully-fledged wars in many AIDS-affected countries – especially in sub-Saharan Africa – steadily escalated. These conflicts have increasingly exposed the civilian populations, particularly the children, to great suffering and caused a rise in the number of refugee and internally displaced children with no access to food, fresh water and health care.

<table>
<thead>
<tr>
<th>Refugees</th>
<th>IDPs</th>
<th>Total</th>
<th>Share</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rwanda</td>
<td>1,545,000</td>
<td>500,000</td>
<td>2,045,000</td>
</tr>
<tr>
<td>Angola</td>
<td>313,000</td>
<td>1,500,000</td>
<td>1,813,000</td>
</tr>
<tr>
<td>Liberia</td>
<td>725,000</td>
<td>1,000,000</td>
<td>1,725,000</td>
</tr>
<tr>
<td>Sierra Leone</td>
<td>363,000</td>
<td>1,000,000</td>
<td>1,363,000</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>500,000</td>
<td>111,000</td>
<td>611,000</td>
</tr>
<tr>
<td>Mozambique</td>
<td>97,000</td>
<td>500,000</td>
<td>597,000</td>
</tr>
<tr>
<td>Eritrea</td>
<td>325,000</td>
<td>200,000</td>
<td>525,000</td>
</tr>
<tr>
<td>Burundi</td>
<td>290,000</td>
<td>216,000</td>
<td>506,000</td>
</tr>
</tbody>
</table>

Source: Cornia and Mwabu 2000.

**Measurement error:** Any empirical analysis of the causes of child mortality is influenced by the quality of the data that – in the absence of survey data – are obtained by extrapolating the pre-AIDS trend, an approach that can lead to underestimation. However, the distortion can be tackled by introducing a dummy variable
(NOSURVEY) that takes the value of 1 in case there is no survey for the years of rapid increase in HIV prevalence.

Cornia and Zagonari (2002) built an eclectic model of child mortality, comprising five sets of explanatory variables, i.e. (i) AIDS-related variables: the prevalence of HIV, the type of virus (whether HIV-1 or HIV-2) and the coverage of PMTCT; (ii) the usual determinants of child mortality: family income per capita, income distribution, female literacy, access to fresh supply; (iii) the coverage of the main health programmes for children; (iv) the impact of large-scale conflicts, disasters and humanitarian emergencies affecting 10 per cent or more of a country’s population; (v) the lack of recent survey data on child mortality. The model can be written as follows:

\[ U5MR = f ((HIV, DUMMY HIV2, PMTCT), (GDP/C, GINI, FL, WS), (DC, IMM, ORT, BF), (CONF), (NOSURVEY)) \] (1)

Before carrying out a regression analysis, Cornia and Zagonari (2002) tested the model and found that there appeared to be an upward shift in both child and infant mortality during the period 1995–2000, but in countries lacking recent U5MR survey data, the test shows that such effect is significant only for the countries without surveys after 1994. Also, HIV-2 appears to have a statistically significant greater impact on U5MR than HIV-1.

The factors that appear to have the strongest impact on child mortality are (in descending order of importance): female illiteracy, access to fresh water, DPT coverage\(^2\) and income per capita. The result confirms that income per capita does not appear to be – as often argued – the most important determinant of child health, and that female literacy has the greatest impact on child mortality. As expected, immunization has a greater impact on child mortality than on infant mortality.

HIV prevalence and – to a lesser extent – the frequency and intensity of natural and artificial disasters are also strongly significant. The coefficient of HIV adult prevalence was found to be 1.93. This means that, in countries where adult prevalence had risen by 10 percentage points, U5MR rose – all other things being equal – by 19.3 points per thousand. This result confirms that the effect of HIV on U5MR was almost imperceptible in countries where adult prevalence remained below 2–3 points. Expanding the coverage of maternity care and oral rehydration therapy by 10 percentage points was found to reduce U5MR by 5.4 and 0.2 points per thousand. The impact of such programmes is thus considerably less pronounced than that of a similar improvement in female illiteracy (that would reduce U5MR by no less than 11 U5MR points), coverage of fresh water supply (reduction of 2.6 U5MR points) and DPT (reduction in 5.8 U5MR points). But the impact on U5MR of maternity care and oral rehydration therapy improved markedly when women were literate and better able to understand and benefit from such programmes, confirming prior findings about the benefits of female education and awareness on the impact of a broad range of health interventions.
Cornia and Zagonari (2002) also attempted to measure the impact of breastfeeding during the first three months and between 6 and 9 months of age. The issue of breastfeeding in HIV-affected countries is controversial, as it tends to increase the risk of mother-to-child transmission. In low- and middle-income countries, breastmilk substitutes are often associated, however, with an even greater risk of mortality due to diarrhoea and undernutrition. The results of the regression estimates show that breastfeeding between 0–3 months of age (but not between 6 and 9 months) was found to significantly reduce child mortality. An increase of 10 percentage points in the 0–3 month breastfeeding rate reduces U5MR by 2.6 points per thousand, and this effect increases in case of literate mothers.

Table 7. Impact on U5MR of a variation in the selected variables

<table>
<thead>
<tr>
<th>Impact on U5MR of a 10% increase in HIV adult prevalence, or of the presence of conflicts, or the HIV-2 virus</th>
<th>Impact on U5MR of a 10% increase in selected programmes</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV RATE</td>
<td>19.29</td>
</tr>
<tr>
<td>CONF</td>
<td>15.50</td>
</tr>
<tr>
<td>HIV-2</td>
<td>13.11*</td>
</tr>
<tr>
<td>WATER</td>
<td>-2.64</td>
</tr>
<tr>
<td>DC</td>
<td>-5.44</td>
</tr>
<tr>
<td>ORT</td>
<td>-0.22*</td>
</tr>
<tr>
<td>BF 0-3</td>
<td>-2.63</td>
</tr>
</tbody>
</table>

Source: Calculation by authors.
Notes: * Indicates that the parameter is not statistically significant though it has the correct sign.

Table 7 points to a few conclusions about child mortality: First, the rate rose in all countries where adult prevalence exceeded 6.5 per cent and in a few ‘failed states’ with a lower prevalence but stagnant coverage of child health services. Due to a lack of data on paediatric HIV it is not possible to differentiate between the effects of mother-to-child transmission and impoverishment induced by HIV, though evidently most of the observed increase in U5MR can to be attributed to the first factor. This is a strong rationale for stepping up programmes to provide universal coverage of nevirapine to newborns. Second, while ethnic conflicts exacerbate child mortality, child health interventions such as immunization, oral rehydration therapy, delivery care, breastfeeding and child nutrition appear to have a significantly positive effect on child mortality, especially when the mothers are educated. Unfortunately, the favourable impact of these programmes is more than offset in countries with high HIV adult prevalence. Pending an expansion of antiretroviral programmes for infants, a 10 per cent rise in adult prevalence requires an expansion of 15 points in all the child health programmes discussed above. This is certainly a difficult objective in economies impoverished by HIV, but one that should be given top priority by policymakers.
Health sector responses to the HIV and AIDS challenge

The response to the HIV pandemics has varied substantially across countries. Some – such as Senegal and Thailand (chapters 3 and 5) – launched a nationwide HIV prevention programme in the early stages of the epidemic and were thus able to control and then reduce its prevalence. Even these ‘model’ countries, however, are only now beginning to deal with the treatment of the HIV-positive people. Other countries – as in Uganda (chapter 2) – prevented the spread of the epidemic but only when prevalence had reached 10 per cent. Some nations – such as China and South Africa (chapters 4 and 6) – only recognized the implications of HIV with considerable delay, so are still unable to control its spread and will have to face a rise in both HIV adult prevalence and, possibly, in U5MR in the years ahead.

Prevention

Based on current growth rates, each HIV-infected person is currently infecting 2.4 other people, on average, before dying. In order to control HIV, the number of people infected during the lifetime of each case has to be reduced to 1, while to eliminate it, the number of transmissions should be reduced to less than 1 per case, a reduction of 60 per cent over current levels. There exists quite a wide range of effective techniques to interrupt or reduce transmission of HIV.

Main prevention programmes

Information and awareness-raising campaigns: These include a variety of communication campaigns carried out through radio and TV spots, popular theatre and peer education that aim to increase awareness of the way HIV is transmitted and to modify sexual and other risky behaviour such as high alcohol consumption. Such programmes do not focus only on the passive transfer of knowledge but also on teaching empowering life skills.

Provision of condoms, especially among target groups (sex workers, IDUs, young people, people with high mobility, etc.). The experience of Senegal, Thailand and Uganda and – more recently – Zambia, suggests that increased condom usage rates reduce HIV prevalence. Bought in bulk, a condom costs $0.03, so supplying an average of 25 condoms to the 800 million sexually active men in HIV-affected countries annually would require 20 billion condoms, at a cost of $600 million, i.e. $0.20 per capita or about 0.03 per cent of those countries’ GDP.

Safe blood transfusion: In the United Republic of Tanzania, it has been demonstrated that safe blood transfusion can be achieved for an annual expenditure of $0.07 per capita. Blood testing is labour intensive and so costs would be higher in high-wage countries. At a cost of $0.10 per capita, this measure would cost 0.02 per cent
of GNP, affordable in all countries. However, infection through blood contamination is a small fraction of total transmission.

Testing and treatment of sexually transmitted infections (STIs): Treating all STIs would reduce the risk of transmission by about half. In Kenya, STI therapy is mainly provided at the hospital level at a cost of $30–200 (Rachier 1999), but in the United Republic of Tanzania, it was estimated that STI testing, treatment and counselling could be provided for $1 per capita. Allowing $1.50 per head, the total cost of covering all those eligible in the 60 most affected countries would be $2.25 billion a year, or 0.2 per cent of their GNP.

Circumcision: Epidemiological surveys show that the HIV epidemic is much less severe in countries where male circumcision is widely practised, including in many countries in West and North Africa. As circumcision is estimated to have a 50 per cent protective effect, it is probably the single most cost-effective intervention. At a unit cost of approximately $1.00, universal male circumcision could probably more or less stop the epidemic, on its own, at a one-off cost of $500 million – or 0.2 per cent of the GNP of the countries affected. This is clearly a very culturally sensitive issue, but it has been asserted that a modest fee for service payments to providers and the provision of certificates would greatly increase circumcision rates.

Prevention of mother-to-child transmission (PMTCT): Mother-to-child transmission can be greatly reduced by a short course of antiretroviral therapy. Implementation of such a programme requires that all pregnant women be screened and counselled and, if necessary, treated. Screening costs only about $2 per test. With the recent price reductions of drugs, treatment for those affected is relatively low and the cost of counselling can be estimated at $1 in a low-income economy.

Voluntary counselling and testing (VCT) among selected populations (pregnant women, sex workers): VCT is normally considered an essential component of behavioural change programmes. In Uganda, it costs $14 per client, but those attending tend to self-select. Per capita costs at a national level would be under $1, since retesting is not required on an annual basis. However, there is insufficient evidence of impacts on behaviour change and transmission rates to rely on it as a key to prevention (Kaleeba and Kalibala 1997).

Quarantine: Isolation of HIV-positive individuals is rarely practised. Cuba’s compulsory testing of 13 million people and the establishment of sidatorios were exceptional measures that did result in the HIV prevalence remaining very low, but quarantine and compulsory testing remain highly controversial as they infringe on the rights of those who are HIV-positive.

The main problems identified in the prevention programmes are:

1. Information campaigns and promotion of condom use. Evaluations of information and condom distribution campaigns show that levels of awareness about
HIV and its transmission modes do rise, but only after a considerable time lag. Moreover condom usage is frequently limited, due to distribution problems, religious institutional resistance and lack of behavioural change (Caldwell 2000).

2. PMTCT and treatment of STIs. Although antiretroviral treatment for pregnant women and newborns is cost-effective, such programmes are limited in scope, even in Thailand (chapter 5). Voluntary HIV testing remains an obstacle to the expansion of the programme. This is also true of STI prevention and treatment, particularly in countries with weak health infrastructures (Gibney et al. 1999).

Mitigation

There has been a wide variety of therapeutic responses to HIV. UNAIDS (2000a) refers to the three packages classification:

i) **The essential package** includes voluntary HIV testing and counselling, psychological support for HIV-positive people and their families, treatment of pneumonia, oral thrush, vaginal candidiasis and pulmonary TB (DOT), and prevention of infections for symptomatic HIV-positive people. Such a package is delivered through home-based care via community or hospital-instituted schemes, hospice-based care, or by subcontracting NGOs. But these interventions tend to cover only a low proportion of those affected (e.g. less than 10 per cent in Zambia and Zimbabwe; Gilks 1998).

ii) **The intermediate package** includes all interventions included in the essential package, plus active case finding and treatment and preventive therapy for TB for HIV-positive people, systematic antifungal treatment, treatment of Kaposi sarcoma with essential drugs, surgical treatment of cervical cancer, treatment of extensive herpes. Such a package is relatively widespread and cost-effective. The inclusion of proactive TB prevention and therapy is essential as it is the leading HIV-associated opportunistic disease in low- and middle-income countries. Success in TB control has been largely dependent on the strength of the whole health care system. A review of some 30 published cost studies from low-income sub-Saharan African countries estimates that the costs of palliative care, together with care for opportunistic infections, per patient per year ranges between $247 and $359 depending on the level of coverage. In middle-income African countries, such as Botswana, Mauritius, Namibia, South Africa and Swaziland, the cost of the basic package would be $471 to $698. But O’Malley (1998) notes that in Burkina Faso, community groups rallied to deliver care to patients with HIV-related illness in highly underserved areas for only $20 per month.

iii) **The advanced package** includes all interventions included in the essential and intermediate packages plus ARV therapy, and diagnosis and treatment of opportunistic infections difficult to diagnose or expensive to treat.
Treatment with antiretrovirals

Triple combination therapy (known also as highly active antiretroviral therapy – HAART), entails an individualized combination of three different drugs, taken for life and continuously followed up with monitoring and testing.

While such therapy has been common for over a decade in the industrialized nations, where it raised substantially the survival and quality of life of patients with HIV-related illness, despite recent reduction in drug costs, it is still rare in low-income countries. In Uganda, in the year 2000, only 1 per cent of the HIV-positive people had access to it (Wendo 2001).

The situation is better in countries with medium GDP per capita, greater coverage of health insurance, lower prevalence and the capacity to manufacture ARV drugs. Brazil’s experience has been the most successful. The National Network of Laboratories supports the drug distribution programme with 133 testing and counselling centres and 424 drug dispensing units. In 1992, the Brazilian authorities decided to manufacture generic ARV drugs, so that they were able to deliver cheap home-produced drugs to 90,000 people, and thus reduced HIV-related mortality by 50 per cent between 1996 and 1999, saving $506 million on hospitalization and treatment of opportunistic infections from 1997 to 1999 (Sarna 2001, Teixeira 2000).

The main obstacle to the extension of antiretroviral therapy coverage, besides cost, is the complexity of the protocol. The drugs have to be administered under close medical supervision and require an advanced laboratory infrastructure to control possible side effects and carry out tests. An additional problem is that some patients appear either not to tolerate the ARV drugs or to comply only occasionally with the daily drug-taking routine, thus reducing the effectiveness of the therapy.

Best practice policy responses

Best practice policies clearly vary from country to country, according to the economic and social situation, but 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 Senegal and Uganda) and social mobilization (as in Thailand) and demands – to start with – a clear recognition of the HIV problem and of its impact on society.

The initial successes recorded in the field of PMTCT and other preventive programmes – such as blood screening and the introduction of mono-use syringes – show that they are very cost-effective, both in terms of lower IMR and U5MR and savings on the costs of treating paediatric AIDS cases. PMTCT is affordable even in low-income economies with high prevalence.

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, so this is an activity that
requires supporting efforts in the fields of privacy protection, counselling and treatment with palliative care.

**Intensifying efforts at mitigating the impact of HIV on people and the health system**

These measures have the advantage of lengthening life expectancy, improving the quality of life and the social usefulness of HIV-positive people by treating those infections that most frequently kill them.

**An overall effort at strengthening the primary health care:** In parallel with the spread of the HIV virus, several countries have experienced a weakening of the PHC system. So, a first response must be in the field of personnel supply and training. Secondly, any urban vs. rural and regional imbalances in the infrastructure need to be corrected. Binswanger (2001) suggests, for instance, that in Uganda the number of patients on ARV therapy can rise fivefold from 1,000 to 5,000 by better use of the existing infrastructure, while the establishment of three regional centres can increase access to ARV treatment for 10,000 patients at $100–150 per patient.

A first 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 and non-HIV-related ailments by strengthening those programmes, such as the Essential Drugs Programme, that play a key role in the response to AIDS and other diseases. In view of their limited development, such programmes need to be sustained and, in many cases, expanded, as indicated by table 8.

**Table 8. Estimated number of HIV-infected people and their access to essential drugs in 1999 in some African countries**

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of HIV-infected people</th>
<th>Access to essential drugs*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burkina Faso</td>
<td>350,000</td>
<td>60%</td>
</tr>
<tr>
<td>Côte d'Ivoire</td>
<td>760,000</td>
<td>80%</td>
</tr>
<tr>
<td>Kenya</td>
<td>2,100,000</td>
<td>35%</td>
</tr>
<tr>
<td>Nigeria</td>
<td>2,600,000</td>
<td>10%</td>
</tr>
<tr>
<td>South Africa</td>
<td>4,200,000</td>
<td>80%</td>
</tr>
<tr>
<td>Uganda</td>
<td>820,000</td>
<td>70%</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>1,500,000</td>
<td>70%</td>
</tr>
</tbody>
</table>

Note: * Access to minimum of 20 most essential drugs continuously available at public or private health facilities within 1-hour walk.

The treatment of opportunistic infections has so far been carried out in a hospital setting and is, for this reason, rather costly. This requires a redefinition of the management of TB and similar diseases through the development of community
and home-based care and greater use of the district health care infrastructure that can greatly reduce costs (Floyd and Gilks 1997).

Barnett et al. (2001) discuss the contracting of NGOs in Brazil and Guatemala as a mechanism to deliver essential components of HIV care such as VCT and palliative care, improving both the quality and extent of the programme while reducing its cost.

**Gradually making ARV treatment accessible to all**

Despite many obstacles, a gradual expansion in ARV coverage would bring notable benefits. The main arguments in its favour are: First of all, lack of treatment would abandon 36 million infected adults and children to certain death. Although there are many other diseases that are endemic in the developing world, none of them is as lethal as AIDS. Second, the possibility of treatment is necessary to optimize prevention, as in the absence of a cure, there are no incentives to take an HIV test. Third, treatment reduces the hospitalization and drug costs for palliative care and the treatment of opportunistic infections. Fourth, a gradual expansion of the treatment with antiretrovirals would involve the strengthening of the overall health system. Finally, treatment with antiretrovirals would avoid a number of the devastating effects that cripple HIV-affected economies, including high mortality and attrition rates among people in the most productive age group, the impoverishment of a large section of society, and the social stigma and deprivation experienced by a mounting number of orphans.

**Reducing the cost of ARV drugs:** The cost of antiretroviral therapy varies, depending on the country’s capacity to manufacture domestically or to import generics from other low- and middle-income countries, but the price of both branded and generic antiretrovirals is declining. The countries that have expanded treatment with ARV the fastest are Brazil, India and Thailand, all of which can produce most of the drugs and distribute them through the public health care sector or pharmacies specializing in the sale of generic drugs (Saavedra 2000).

The UN can help in reducing costs by assisting with international procurement, quality assurance, and certification, as previously done for the UNICEF–WHO Essential Drug Programme that purchased generic drugs on the international markets in bulk, at prices up to 50 times less than the price of branded products.

There are a number of possible strategies for reducing the cost of ART further. These include drugs being given or sold at discount by the pharmaceutical companies, as in Senegal, the adoption of dual pricing systems (as proposed by some transnational corporations), or both production and import of generic drugs competing on the open market with branded products. Success in reducing the cost of antiretroviral drugs could mean that even some low-income countries could start to gradually expand the number of adults being given ART. With the spread of the generic drugs and the simplification of therapeutical protocols, the target for a reduced price is $300 a year, a sum equal to the entire annual income of many people
in HIV-affected countries. This need not necessarily matter from an economic and public health perspective. If prevalence is low, then the cost of treatment could be subsidized through health insurance, public spending or community mechanisms. The impact that such arrangements would have on the proportion of the national GDP required to treat all those infected is a function of prevalence, drug price and GDP per capita in the state or community concerned, and can easily be calculated, using the following formula:

\[
\text{Per cent of GDP needed} = \frac{\text{prevalence (for the entire population)} \times \text{drug cost per year}}{\text{GDP per capita}}
\]

If the prevalence of the entire population (i.e. not only those 15–59 years of age) is 1 per cent, the treatment costs $300 per year, and the average GDP per capita is $300 per year, then only 1 per cent of GDP would need to be spent on antiretroviral treatment. Similarly, if 10 per cent of the community were infected, the drug costs $300 per year, and average per capita income is $300, then 10 per cent of the GDP would be required. In Brazil, which has a low HIV population prevalence and a relatively high GDP per capita, all cases could be treated for less than 0.05 per cent of GDP, as, indeed, they are for free by the health service. In Botswana, where the population prevalence is one of the highest in the world, a drug price of $300 per year would require spending about 2 per cent of GNP, slightly more than Botswana’s total public health expenditure. An important and difficult, but yet feasible, national effort would be required to provide treatment for all cases. The situation is more problematic in countries such as Kenya with medium prevalence but a low GDP per capita, meaning that about 10 per cent of the national GDP would be required to cover all infected people (Kimani 2000). This percentage is almost Kenya’s total government expenditure, so it is clearly impossible to allocate such an amount of money to treatment of just one disease. But, without massive external and domestic effort to extend treatment, about 10 per cent of the population of Kenya will have died from AIDS within six to seven years.

Table 9. Simulation of the percentage of GDP required to treat the HIV population under a given assumption about the cost of the treatment, prevalence and GDP per capita

<table>
<thead>
<tr>
<th>Country</th>
<th>Population prevalence %</th>
<th>Hypothetical ‘low’ annual drug price $</th>
<th>GDP per capita $</th>
<th>% of GDP required for ARV treatment of all infected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brazil</td>
<td>0.5</td>
<td>300</td>
<td>3,000</td>
<td>0.05</td>
</tr>
<tr>
<td>Botswana</td>
<td>20</td>
<td>300</td>
<td>3,000</td>
<td>2</td>
</tr>
<tr>
<td>Kenya</td>
<td>10</td>
<td>300</td>
<td>300</td>
<td>10</td>
</tr>
</tbody>
</table>

Source: Author’s calculations.
Notes: Figures used here are rounded off for ease of calculation. Except for the drug price, which is still significantly higher than $300 for a year of treatment, the data closely approximates the true situation in the countries considered. If the drug price in the country were double the figure used here, then the proportion of GNP required would also be doubled.
These figures are purely conjectural but help identify the conditions in which treatment can gradually be extended. While cost-sharing in various forms may be of assistance in low-prevalence, high-income countries, the necessary total economic resources are simply not available in high-prevalence, low-income countries, even if costs fall to $300 per year. While this analysis does paint a rather bleak picture for some countries, it can also serve to give some indication of what an affordable price might be. In a country such as Kenya, treatment of all cases would require that the cost of one year of treatment with ARVs be reduced to $20–30.

Introducing simpler therapeutic protocols: The second obstacle to the extension of HIV treatment is the complexity of the treatment protocols and the weak public health infrastructures, but considerable experimentation is already going on in this area. Given the shortage of doctors in affected countries, they could be replaced by nurses with specific training in the field to administer and monitor the treatment. In Haiti, there are innovative attempts to implement treatment with a community-based ‘barefoot doctor approach’, entailing a simplification of the tablets-taking cycle (Farmer et al. 2001).

Finally, there is a need to develop simpler health delivery systems, based on outpatient, home-based and hospice care. The vast literature on care provision generally shows that community and home-based care – particularly if carried out in collaboration with provincial hospitals – is as effective as hospital-based care, and considerably less costly. In urban and periurban areas, this approach noticeably reduces administrative and hospital costs and costs for transport, meals and other items paid by the patients themselves (Haile 2000, Drew et al. 1997). Through such savings, more eligible people could be covered. Some studies, such as Hansen et al. (1998), show that home-based care is not cost-effective for patients with HIV-related illness in scattered hamlets in rural areas. The cost of a visit in a rural home-based care programme in Zimbabwe was equal to the cost of 2.7 inpatient days in a district hospital as two thirds of the cost was spent just getting to the patient.

Improving resource mobilization and diversifying the sources of funding: While drug procurement policies and simplification of the therapeutic protocols may help reduce the unit cost of treatment, the proposed gradual expansion of ART entails the mobilization of additional health resources. As noted above, in low-income countries, the increase in total health expenditure during the last 10 years was borne by the household sector, a fact that may have entailed the exclusion of the poor from health care.

According to UNAIDS in 2004, global spending on AIDS was just under US $5 billion in 2003, but by 2007 US $20 billion would be needed for prevention and care in low- and middle-income countries (UNAIDS 2004). This would cover ART for just over 6 million people, support for 22 million orphans, HIV counselling and testing for 100 million adults, AIDS education for 900 million students and peer counselling for 60 million young people not in school. But the range of the
plausible estimates varies a lot. While this is a huge sum, the problem of financing HIV and AIDS care will be particularly intense in low-income countries. In countries such as Argentina, Brazil and Mexico, the cost of an ambulatory service package was estimated in 2001 to represent respectively 0.02 per cent, 0.11 per cent and 0.06 per cent of GDP.

The situation in low-income African countries is more complex. Examples of different health financing approaches are available (Contact Group meeting 20 May 2001; see also case studies by Abt Associates on Guatemala, Rwanda and Senegal). Except for a few growing African economies – such as Uganda – the increase in HIV resources cannot come from individual patients. Greater efforts ought to be placed therefore on increasing resources in ways that would distribute more equitably the burden of HIV within the countries affected and internationally. This objective could be reached by means of: co-payments by well-off individuals; the development of risk-pooling arrangements at the local level; the development of health insurance for those employed in the formal economy; the re-allocation of public expenditures from low to high priority sectors; and an increase in earmarked taxation. International resources need also to be increased through debt-for-AIDS swaps or fresh money raised from the Global Health Fund adopted by the G-8.

An important component of the financing strategy against HIV and AIDS is risk-pooling arrangements to spread the cost of HIV treatment among a broad pool of people and to avoid the impoverishment of HIV-affected families. Such arrangements include the national health insurance (fairly developed in South Africa and Zimbabwe) and municipal or provincial pre-payment schemes (common in Thailand). Public funding is the broadest form of collective insurance and several countries subsidize the treatment of HIV to some extent. Mexico covered 76.1 per cent of the total health expenditure but only 49 per cent of the HIV expenditure. The state of Sao Paolo in Brazil and Thailand, in contrast, subsidized 36 per cent and 76 per cent of the cost of the HIV treatment but only 20 per cent and 55 per cent of the general health care.

Traditionally, private companies have turned a deaf ear to the possibility of insuring their staff against HIV. Things are starting to change, however. The power company of Côte d’Ivoire, for instance, realized that it can be cheaper to cover the cost of ARV treatment than that of extended illness and hospitalization of HIV-positive employees. Also, inability of entering an ARV treatment programme can result in higher payments for disability allowances or survivor benefits, and in high costs of recruiting and training replacement employees (Binswanger 2001). Moreover, a private insurance company working in East Africa has been able to cover treatment for enrolees in the early stages of the disease (Feeley 2000). Insurance companies in Mexico took interest in a re-insurance programme for asymptomatic HIV-infected people. Be that as it may, it is clear that extending health insurance holds a considerable potential for
making ARV treatment available to many infected people in middle-income countries, though in these countries, the spread of health insurance will be limited by a high unemployment rate and the size of the informal sector.

In low-income countries, risk-pooling arrangements have to expand massively. Mutual health organizations are a form of community-based and non-profit health insurance that enable members to pay dues when they are well and little or nothing when sick. From 1999 to 2000, the Project of Health Reform team developed performance indicators for projects undertaken in Côte d’Ivoire, Ghana and Senegal. They showed that these health insurance schemes can represent a short-run solution (until viable national solutions emerge), but for priority services only. Also such schemes seem unable to reach the extremely poor.

Finally, in low-income countries, the public budget has a key role to cover the poor and, especially, the extremely poor. And this brings us back to the decade-long debate on taxation levels and public finance priority in low-income countries. Nothing new can be said here in relation to the debate of the 1980s and 1990s, which has highlighted the overall benefits of a pro-poor allocation of public expenditure and the importance of generating adequate levels of revenue. The only additional argument that can be made here is that the cost of inaction is far bigger than in the case of low expenditure in health and education.

Balancing prevention and treatment in countries with different infection rates

The prior sections have suggested that the challenge of AIDS requires simultaneous efforts in the fields of prevention, mitigation and treatment. Given that public resources assigned to such a response are extremely limited in most countries, the policymaker has to choose how best to allocate them among competing alternatives. The choice of the optimal mix of interventions is obviously conditioned by the HIV prevalence of a country, its GNP per capita and distribution; the strength of its health infrastructure; the relative cost and efficacy of various interventions; the coverage of health insurance; the strength of pressure groups aiming at diverting public expenditure to their advantage; and the time horizon within which any programme has to be implemented.

So far, the literature has recommended concentrating the response to AIDS on prevention, palliative care and the treatment of opportunistic infections, especially in countries with high prevalence. The main reason adduced to justify this position is the higher unit cost of treatment. This approach is rational when policy is guided by the objective to ‘minimize HIV prevalence’. Even in this case, however, a truly rational decision must take into account the interaction between prevention and treatment. In fact, treatment helps optimize prevention, because in the absence of a cure, people have no incentives to undergo voluntary testing and to modify
their sex behaviour. In addition, treatment reduces the viral load and thus mini-
mizes the probability of transmitting the virus to others.

The optimal mix of interventions may also change if the dominant policy objective is ‘maximizing the years of life’. In this case, the benefits of ARV treatment would emerge more clearly as such therapy lengthens the life of those already infected. Prevention also lengthens the life of those reached by preventative messages, though these do not always entail a behavioural modification. The average cost per person who effectively modify sex behaviour is thus much higher. If the number of those reached by prevention programmes who change their behaviour is half of all those exposed to the message, costs per capita of prevention rise to $20–100 per capita. Moreover, the benefits of ARV treatment would be even more evi-
dent if the dominant policy objective were the full evaluation of all costs and benefits of an anti-AIDS strategy. In this case, one should include among the benefits of ARV treatment a slower rise in the number of orphans lacking parental guid-
ance; the lower demand for sickness and orphan allowances and early retirements;
the savings on palliative care and the cure of opportunistic infections; the loss of in-
come by the working-age population infected or dead. Finally, as repeatedly noted,
the cost of the antiretroviral treatment has been falling rapidly during the last 2–3
years, while the international aid targeted to the treatment of HIV is rising (as sug-
gested by the International Health Fund of $1.3 billion launched in 2001).

All these arguments suggest that the policy response to HIV and AIDS may change, depending on whether the effects of treatment on improving the efficacy of preven-
tion is taken into account, and the choice of the objective – to minimize HIV preva-
lence, or to maximize the years of life for PLHIV. The choice of the best policy mix
can typically be represented as an optimization problem. Illustrated in annex 1 is a
simple model, identifying the optimal combination of prevention and treatment meas-
ures given different assumptions concerning their costs and effectiveness, the choice
of policy objective and the interactions between prevention and treatment.

Two numerical examples illustrate this point. In the first case, the objective is to
minimize prevalence. Given the real (i.e. observed) values of the parameters meas-
uring the effectiveness of prevention and treatment activities, the public health ex-
penditure for HIV will be almost entirely assigned to prevention, with ARV
treatment receiving residual funds only (see table 10). Furthermore, even if the rel-
ative cost-efficiency of ARV treatment improves because, for instance, of a moder-
ate fall in the cost of ARV (under hypothesis A the unit cost of treatment \( c_t \) is 15
times greater than the unit cost of prevention, while under hypothesis B it is 10
times greater), the allocation of public resources does not change, with ARV treat-
ment receiving residual funds only. Likewise, even if the relative efficacy of pre-
ventions falls sharply, the percentage allocation of public expenditure assigned to
prevention still does not decline.
Table 10. Percentage distribution of public expenditure between prevention and treatment with antiretroviral therapy, assuming the policy is to minimize HIV prevalence

<table>
<thead>
<tr>
<th>Objective function: minimize prevalence</th>
<th>Percentage of health expenditure assigned to preventative activities</th>
<th>Percentage of PLHIV treated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypothesis A: unit cost of treatment is 15 times that of prevention</td>
<td>86%</td>
<td>10%</td>
</tr>
<tr>
<td>Hypothesis B: unit cost of treatment is 10 times that of prevention</td>
<td>81%</td>
<td>20%</td>
</tr>
<tr>
<td>Hypothesis C: unit cost of treatment is 10 times that of prevention and efficacy of prevention falls to one quarter of its original value (from $z=5$ to $z=1$)</td>
<td>81%</td>
<td>20%</td>
</tr>
</tbody>
</table>

Note: in hypotheses A, B and C all parameters of the model are unchanged (i.e. $z_t=2$, $z_{te}=0$, $z_{tp}=5$, $c_p=1$, $r_t=0.1$, $e_0=1.1$, $d=0.1$) except that under hypothesis C in which it is assumed that $z_{tp}=4$.

By contrast, if the objective of the policymaker is to maximize the numbers of years lived (either through prevention or through care) then, given the same realistic value of the parameters, currently relevant costs and the effectiveness of prevention and treatment activities, the allocation of public resources will be assigned to prevention to a lesser extent (see table 11). Furthermore, if the relative cost-efficiency of treatment improves (because, for instance, of a fall in the cost of ARV) then the proportion of public resources allocated to treatment will reach a consistent amount. Likewise, if the efficacy of prevention falls, the share of resources to be assigned to the therapy with antiretrovirals rises further.

Table 11. Percentage distribution of public expenditure between prevention and treatment with antiretroviral therapy, assuming the policy is to maximize the number of years lived

<table>
<thead>
<tr>
<th>Objective function: maximize the number of years lived</th>
<th>Percentage of health expenditure assigned to preventative activities</th>
<th>Percentage of PLHIV treated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypothesis A: unit cost of treatment is 15 times that of prevention</td>
<td>79%</td>
<td>14%</td>
</tr>
<tr>
<td>Hypothesis B: unit cost of treatment is 10 times that of prevention</td>
<td>33%</td>
<td>72%</td>
</tr>
<tr>
<td>Hypothesis C: unit cost of treatment is 10 times that of prevention and the efficacy of prevention falls to one quarter of its original value (from $z=5$ to $z=1$)</td>
<td>24%</td>
<td>82%</td>
</tr>
</tbody>
</table>

Note: in hypotheses A, B and C all parameters of the model are unchanged (i.e. $z_t=2$, $z_{te}=0$, $z_{tp}=5$, $c_p=1$, $r_t=0.1$, $e_0=1.1$, $d=0.1$) except that under hypothesis C in which it is assumed that $z_{tp}=4$. 


References and Bibliography


Notes

1 A review of public expenditure changes during periods of budgetary stringency (Pinstrup-Andersen, Jaramillo and Stewart 1987) shows that, of all types of expenditures, capital expenditure is invariably cut the most.

2 The use of measles, polio or BCG coverage – instead of DPT coverage – yields practically identical results.

3 If a good carries very high public health benefits, as is the case for vaccines for infectious diseases, it is normally assumed that the correct price for that commodity is zero. A similar conceptual framework could be applied to condoms. It is hard to imagine that the campaign to eliminate smallpox would have been successful if people had been charged for the vaccine.
Annex 1

A Simple Model to Choose the Optimal Policy Mix Between Prevention and Treatment

(i) Modelling the effects of treatment on prevention and vice versa. The purpose of this model is to discuss the choice of the optimal mix of prevention and treatment policies. For the sake of simplicity we will compare the effectiveness and costs of two alternative policies only: a combination of the several preventive policies (condom, MTCT, circumcision, blood screening programmes, information campaigns promoting a decline in the number of sexual partners, a more consistent condom use, and an increase in the age of sexual debut) and a policy focusing on the treatment of HIV-positive people with antiretrovirals. We first normalize the population size to 1. For the sake of simplicity, we will compare the effectiveness of the two policies chosen only at time 0 and time 1 where the difference between time 0 and time 1 is equal to the average number of years gained by an infected person undergoing treatment with antiretrovirals.

The evolution over time of HIV prevalence can be described by a continuous nonlinear function where its value at time 1 depends on its value at time 0. At time 1, HIV prevalence would increase (or decrease) with respect to time 0 at a given inertial rate $d$, representing the endogenous dynamics of the epidemics (hereafter called ‘the HIV natural dynamics’) in the absence of any policy measure. The HIV prevalence at time 0 and time 1 are denoted by $r_0 \ (0 < r_0 < 1)$ and $r_1 \ (0 < r_1 < 1)$ respectively. Prevention policy reduces HIV prevalence at time 1 by a factor $(z_p \ x_p)$ where $x_p \ (0 < x_p < 1)$ is the percentage of the population reached by the prevention campaign and $z_p$ represents the effectiveness of the prevention policy in terms of its impacts on awareness improvements and behavioural change. Similarly, the treatment policy reduces HIV prevalence at time 1 by the factor $(z_t \ x_t)$ where $x_t$ is the percentage of the HIV-infected population being treated and $z_t$ depicts the effectiveness of the treatment policy in terms of its effects on virus loads and behavioural change. Therefore, at time 1, the HIV prevalence is formally given by:

$$ r_1 = r_0 \left[1 + d \right] \left[1 - z_p \ x_p - z_t \ x_t \ r_1 \right] $$

At time 1, the proportion of the population still surviving is the proportion of the population not infected at time 1 plus the percentage of people living with HIV under treatment at time 0. Therefore, at time 1, the overall surviving rate is given by:

$$ 1 - r_1 + z_t \ r_0 = 1 - r_0 \left[1 + d \right] \left[1 - z_p \ x_p - z_t \ x_t \ r_1 \right] $$

(2)
Both prevention and treatment policies have costs that are borne at time 0. The costs per year per capita of prevention and treatment are $c_p$ and $c_t$ respectively. However, the health expenditure to be borne at time 0 ($e_0$) is influenced by the following two effects: First, treatment increases the effectiveness (or reduces the average unitary cost) of prevention. It is assumed that $c_p$ decreases by $z_p^t$ for each person with HIV under treatment at time 0. Moreover, a treatment policy improves the perceptions among donors of the robust response to HIV and AIDS by the national government and so triggers an increase in international aid earmarked to HIV and AIDS, which in turn softens the domestic budget constraints. This is shown by assuming that $e_0$ decreases by $z_{te}$ for each person living with HIV under treatment at time 0. Therefore, at time 0, the health expenditure needed in order to implement the chosen combination of prevention and treatment policies can be expressed as:

$$e_0(1 + z_t^t X, r_i) + e_0(1 - z_t^t X, r_i)X_i + c_t X_i, r_i$$  \hspace{1cm} (3)$$

Given these three relations, the policymaker can choose two different policy objectives, i.e. minimize prevalence at time 1 or, alternatively, maximize the number of years lived at time 1. For each of them, given a fixed health budget, we can identify the optimal combination of prevention and treatment measures.

(ii) Solving the model given different objective functions at time 1. If the policy objective is to minimize prevalence at time 1, the optimal solution of equation (1), subject to constraint (3), is expressed by:

$$\min_{x_i, r_i} \quad r_1 - r_i (1 + d_i')(1 - z_r^t X, r_i)X_i - z_t X_i, r_i$$

$$s.t. \quad c_t (1 + z_t^t X, r_i) - c_t (1 - z_t^t X, r_i)X_i + c_t X_i, r_i$$

In contrast, if the objective is to maximize the number of life years saved at time 1, the optimal solution of equation (2), subject to constraint (3), is expressed by:

$$\max_{x_i, r_i} \quad 1 - r_1 + x_i, r_i = 1 - r_i (1 + d_i')(1 - z_r^t X, r_i)X_i - z_t X_i, r_i + x_i, r_i$$

$$s.t. \quad c_t (1 + z_t^t X, r_i) - c_t (1 - z_t^t X, r_i)X_i + c_t X_i, r_i$$
(iii) **Some general analytical results.** The solutions to the first and the second optimization problems (see Cornia and Zagonari 2002) highlight the following general insights: If the optimal proportion of the general population reached by prevention ($x_p^*$) and the optimal proportion of PLHIV undergoing treatment ($x_t^*$) are represented as functions of the effectiveness of prevention ($z_p$) and of the other parameters introduced above to represent the feedback effects between treatment and prevention, three qualitatively different patterns emerge in three subsequent ranges. If $z_p$ takes low values (below a specified $L$), then the general population reached by prevention activities ($x_p^*$) should be constant at a non-negative percentage, while the optimal proportion of PLHIV reached by care activities should be 100 per cent ($x_t^*=1$); if $z_p$ takes intermediate values (between specified $L$ and $H$), then $x_p^*$ is an increasing and concave function, while $x_t^*$ is a decreasing and convex function; if $z_p$ takes high values (above a specified $H$), then the general population reached by prevention activities should be 100 per cent ($x_p^*=1$), while the optimal proportion of PLHIV reached by care activities ($x_t^*$) should be constant at a non-negative percentage. Thus, whichever objective is adopted, the relative costs and effectiveness could lead to a solution whereby a single optimal policy is implemented, or to an intermediate solution whereby both policies are implemented.

Next, comparing the solutions of the two optimization problems led us to deduce that the three relevant subsequent ranges of the effectiveness of prevention activities ($z_p$) for the maximization problem are shifted forward with respect to those for the minimization problem so that $L$ (MAX) > $L$ (MIN) and $H$ (MAX) > $H$ (MIN). Thus, for given relative costs and effectiveness of prevention and treatment, a movement from minimizing HIV prevalence to maximizing the years of life for the general population and for PLHIV could lead to decreasing the optimal proportion of the general population reached by prevention ($x_p^*$) and increasing the optimal proportion of PLHIV treated with antiretrovirals ($x_t^*$). In other words, more of the PLHIV should be given ARV treatment if the policy objective is maximization of the years of life lived, rather than minimization of prevalence.

(iv) **Some numerical examples.** The analytical results sketched above lead us to deduce that relative, rather than absolute, values of both costs and effectiveness of prevention and care activities are the relevant factors driving the allocation of public health expenditure on HIV and AIDS. Let us normalize both $c_p$ and $z_p$ to 1 so that $c_t$ becomes the relative unit cost of care with respect to prevention, $e_0$ becomes the health expenditure per capita per year over the unit cost of prevention, and $z_t$ becomes the relative effectiveness of care with respect to prevention. Numerical simulations are then carried out by assigning to the variables expressing the costs and effectiveness of prevention and treatment activities their values currently observed in real life. In particular, we assume that treatment is twice as effective as prevention, that a 1 per cent increase in the coverage of treatment reduces prevention costs by 50 per cent at 10 per cent HIV prevalence, that available resources
do not depend on the coverage of treatment, and ‘the HIV natural dynamic’ is 10 per cent in the period under consideration. The analytical results, combined with the numerical simulations, allow us to draw the following conclusions:

1. Treatment of a positive proportion of the population is an optimal policy only when the policy objective is to maximize the number of years lived.

2. Resources required to achieve a consistent coverage rate for treatment are lower than usually stated: the tables in the text assume a health expenditure per capita per year only 10 per cent higher than the unit cost per capita per year of prevention.

3. A one third reduction in the unit cost of treatment will make treatment of a substantial proportion of the HIV-positive population an optimal policy even when prevalence is high.
Chapter 11
Programme and Policy Responses to the Impact of HIV and AIDS on Children

Stanley Ngalazu Phiri and Douglas Webb

Introduction

Every 50 seconds, one child dies of an AIDS-related illness and another becomes infected with HIV. Each day approximately 3,700 children are infected by, or die from, HIV and AIDS (UNAIDS 2004). Today, in sub-Saharan Africa, over 12 million children under the age of 15 are orphaned because of AIDS and by 2010 anywhere from 15 per cent to 25 per cent of children in over a dozen countries will be orphaned (UNAIDS, UNICEF and USAID 2004). These figures represent a shocking failure on the part of the global community. Of the estimated 38 million people living with HIV worldwide, 2.1 million are children. Even if a levelling-off of new infections occurs, due to the long incubation period of the virus, mortality rates will not plateau until at least 2020, and the proportion of orphans will remain strikingly high, at least through to 2030 (Levine and Foster 2000).

Policymakers face strong challenges to mitigate the impact of the growing numbers of children orphaned and affected by AIDS. This chapter outlines these challenges and attempts to offer some solutions, although the complexity and dynamism of the debates make even such snapshot analysis difficult. These challenges relate to (a) reaching consensus on policy-related definitions of orphans and children made vulnerable by HIV and AIDS (OVC); (b) the emergence and realization of rights-based approaches to programming for OVC; (c) the explication and scaling up of ‘good’ practices in supporting OVC; (d) the effective flow of ‘resources to the base’; and finally (e) mobilizing political will. These challenges overlap and interrelate, but constitute the key constraints on widespread and effective responses.

Reaching consensus on policy-related definitions

Defining broader child vulnerability in relation to HIV and AIDS is complex. Communities’ own definitions of vulnerability include children who are not classified as
orphans (now agreed to be children aged under 18 who have lost one or both parents), such as disabled or destitute children, who may not necessarily be biological orphans, but may be termed ‘social orphans’. In fact, children start suffering economically, psychologically and in other ways long before they become orphans, i.e. during the period of illness of parents or other adults in the household. This mismatch between a community’s notions of vulnerability and the imposition of external definitions tends to result in a top-down approach that is unlikely to encourage community ‘ownership’ of programme activities. In addition, the use of the stigmatizing term ‘AIDS orphans’ (sometimes interpreted as ‘orphans with AIDS’) creates a situation where other vulnerable children may be left out of assistance activities. Communities know the children about whom they are most concerned, as Williamson and Donahue noted in Malawi: ‘…in other communities, however, orphans appeared to be a primary focus because their needs have been emphasized by external bodies. Some communities were coming to see orphans as a privileged group and resented this displacement because it undermined extended family mechanisms’ (Williamson and Donahue 2001).

Variations in the definition of orphans and vulnerable children and how these relate to globally accepted definitions warrants special attention. The variations are sometimes reflected in policy and legislation encompassing the issues surrounding distinctions between those definitions that are for targeting purposes (programme and project level) and those developed for quantitative use (national level/policy/surveillance and macro-resource allocation decisions).

The term ‘children living with HIV/AIDS’ was adopted by the National HIV/AIDS Care and Support Task Team in South Africa to cover all infected children, children in households where one or both parents are infected, children vulnerable to infection and those in households that have no HIV-positive members but who are affected due to societal impacts, reduced access to services; and those who have been abandoned (Smart 2001). The dangers of using such widespread and inclusive definitions in policy are that targeting of the most vulnerable groups becomes difficult and open to localized (mis)interpretation and abuse, and also that the scale of the problem can appear to be overwhelming, so stifling any concerted response. The problem is defined to a point where meaningful action is seen to be no longer feasible. In the United Republic of Tanzania, the concept of ‘most vulnerable children’ has gained currency and this allows a localized response. Reaching consensus on definitions of children about whom to be most concerned is one of the critical challenges facing all of those involved in responses to the needs of children made vulnerable by HIV and AIDS. What is clear is that orphanhood in and of itself is not the sole valid criterion for assistance.

**HIV and AIDS and children’s rights**

The issue of definitions is pertinent to the emergence of rights-based approaches to supporting children affected by HIV, as questions of vulnerability, categorization.
and targeting are under scrutiny. HIV has many direct and indirect impacts on children’s rights, ranging from the consequences of the psychological impact of losing one or both parents, to reduced access to quality education and health services (see chapters 9 and 10). The Convention on the Rights of the Child (CRC) is underpinned by four major principles:

1. the right to survival, development and protection from abuse and neglect;
2. the right to have a voice and be listened to;
3. the best interests of the child should be of primary consideration;
4. the right to freedom from discrimination.

However, for many children who have been infected or affected by HIV, these rights are being compromised. Children who are themselves living with HIV, or who have lost one or both parents to the virus, often experience discrimination and exclusion from the community as a result of stigma. The growing number of child-headed households also affects the rights of children to education, to rest and leisure, to survival and development, to protection from sexual and economic exploitation, and to protection from abuse and neglect (survey evidence across southern Africa indicates that 1–2 per cent of all households are headed by children). The death of parents and worsening poverty are contributing to the growing number of children working in hazardous and exploitative conditions.

For many children infected or affected by HIV, the fundamental principles of the CRC, especially the rights to non-discrimination, survival and development, are most often compromised. This results from fear of HIV and a lack of understanding of how the virus is transmitted. For infected children, and those perceived to be infected, their supposed impending death is at the root of most discrimination they face. This stigmatization is made worse by the fact that it comes from every section of the community, including other children, guardians, teachers and even parents themselves, especially widows and stepmothers (Alidri 2001). In Malawi, children orphaned by AIDS tend to form their own informal groups as a result of this stigma and exclusion by their unaffected peers (Cook 1998). In some extreme cases, teachers often refuse to allow these children into schools. The tragic case of Nkosi Johnson in South Africa was brought to the world’s attention in 2000. This young boy living with HIV was denied his rights to education and freedom from discrimination. Similar cases were recently reported in Kenya and NGOs are watching for comparable situations across the continent.

**How children’s rights to survival and development are affected by the HIV epidemic**

HIV also affects the survival and development of children through its impacts on health, family livelihoods, social welfare and protection. The impact of HIV on
the health of children relates not only to the growing number of children being infected with HIV, but also to the effects HIV has on access to health care for children who are HIV-negative. As with access to education, stigmatization and discrimination also threaten access to health services. The reduction and reorientation of the family’s income to cover the costs of HIV-related treatments has significant impacts on the health of children. For example, families with one or more members living with HIV will spend a much higher proportion of their income on HIV-related treatments, thereby reducing the income available for general health care, including immunization (see chapters 7 and 8). In Côte d’Ivoire, urban families in which a family member had AIDS were reported to spend four times as much on health care as unaffected families. Also, the parent’s level of illness may make it very difficult for them to provide adequate child care and food or to travel to health centres with their children. In Zambia, households in which the head was chronically ill reduced the area of land cultivated by 53 per cent, compared to those without such an ill adult, resulting in lower food availability (SADC reports referenced in UNICEF 2003). Higher rates of stunting and wasting, as well as more elevated rates of severe or moderate malnutrition, have been reported in orphaned children (Human Rights Watch 2001).

The most significant effect of HIV on the social welfare and protection of children is the disintegration of traditional support structures and ‘social safety nets’. As the number of affected children increases, the capacity of the community to support these children is being stretched significantly. Increasingly, a large proportion of orphans are being taken care of by elderly grandparents who are often old, unable to generate income and may be living in impoverished conditions. Moreover, often these children are orphaned for a second time when their grandparents die.

The death of one or both parents, and the resulting increased household expenditure on health, place more economic responsibilities on children. Many are forced to drop out of school and take up work to contribute to family incomes. In Uganda, surveys reported that 0.25–0.5 per cent of the affected children were not attending school regularly because they had to take care of their sick parents (Gilborn 2000; UNICEF 2003). In Burundi, children in HIV-affected households begin earning earlier than those in unaffected households, becoming involved in petty trading and running errands at the ages of six or seven (Roudy et al. 2001). There is also a growing number of children ending up on city streets. Some children end up working in highly hazardous conditions, such as the informal mining industry, where they risk severe injury. A UNICEF study on HIV and child labour concluded that the epidemic was responsible for pushing a significant percentage of the millions of working children onto the labour market. Rapid assessments in Ethiopia found that more than three quarters of the domestic workers were orphans; in the United Republic of Tanzania, 38 per cent of the children working full-time in
quarrying were orphans; and in Zambia, 47 per cent of the children engaged in prostitution had lost both parents and 24 per cent one parent (UNICEF 2001; 2003).

**Child-focused and rights-based programming**

Rights-based programming implies a holistic approach, dealing with aspects of prevention, care, protection and impact mitigation. A rights-based response also aims to promote the participation of children and young people in the design and implementation of HIV programmes. This is being achieved through the work of key global institutions working for the rights of children by developing a global strategy and policy framework to guide programming for orphans and other children made vulnerable by HIV and AIDS. Five key strategies have been defined (UNICEF/UNAIDS 2004). These aim to:

1. Strengthen the **capacity of families** to protect and care for orphans and vulnerable children, by prolonging the lives of parents and providing economic, psychosocial and other support.

2. Mobilize and support **community-based responses**.

3. Ensure access for orphans and vulnerable children to **essential services**, including education, health care and birth registration.

4. Ensure that **governments protect** the most vulnerable children through improved policy and legislation and by channelling resources to families and communities.

5. Raise awareness at all levels through advocacy and social mobilization in order to create a **supportive environment** for children and families affected by HIV and AIDS.

These strategies are fundamental to effective care and support and to the development of the coping capacities of affected households and communities, with child participation at the centre of the response.

While conceptually rights remain universal, responses must be grounded in local realities, necessitating a needs assessment and social mobilization process far removed from more traditional welfare responses. This is cost- and time-intensive, creating a crisis of capacity, for when the emphasis becomes prioritizing local conditions, the identification of ‘good’ and ‘best’ practices becomes more difficult.

**Defining and scaling up of good practices – doing more of ‘what works’**

A critical challenge is the identification of what constitutes or defines ‘good practices’ and how these can be scaled up to reach more children. The use of the term ‘best
practice’ is problematic and remains valid only at a conceptual level (Webb 2001). There is a wide range of approaches being practised by different organizations, governments and communities for the care of orphans and children affected by HIV and AIDS. Approaches that could go to scale have to be simple, owned and managed in the community, cost-efficient and easy to replicate (Phiri et al. 2001; Foster 2001; International HIV/AIDS Alliance 2001).

Scaling up is threatened by, among other things:

• lack of political support or political interference;
• corruption;
• inadequate dissemination of information on government policies and funding;
• reluctance to enact, modify or implement child protection policies and legislation;
• weaknesses and under-resourcing (human, financial and technical) of state service delivery and coordination of child care systems;
• lack of strategic partnerships;
• lack of integration into, or separate, national costed plans.

Difficulties in scaling up are primarily political. Governments have to be convinced of the political, social and economic costs of inaction. They also have to be convinced of the validity of support models, which may complement or intrinsically criticize government responses by addressing key support gaps. NGOs and CBOs will have differing agendas and governments, acting through the mediation of district and provincial officialdom, can and do opt to disengage with the non-state actors, due either to the perceived threat of interaction or just plain disinterest (Webb 2004). This challenge is considerable in parts of south and south-east Asia, where corruption tends to inhibit local government adoption of NGO responses. This is noticeable in Cambodia, China, India and Viet Nam, where local governments are only just starting to consider the impending orphan, and broader children and AIDS, crisis.

Political constraints notwithstanding, at the implementation level there is a basic set of prerequisite questions before scaling up can begin. These include the nature and extent of pre-existing coping strategies, what structures frame these responses, what could be described or agreed upon as the basic minimum package for an effective response, and how it can be delivered or helped to emerge without eroding community capacity.

Assessing models of care involves answering key questions:

• if and how the model responds to the physical, material, educational, psychosocial, cultural and spiritual needs of orphans and other vulnerable children;
• number and types/categories of needs addressed;
• numbers of children reached;
• degree of ‘child focus’;
• transparency in targeting;
• nature of community ownership;
• sustainability;
• influence on policy at local and national level.

Underpinning these assessment criteria is the search for ‘good practices’.

**Good practices in responding to children affected by HIV and AIDS**

We will consider community-based, as well as institution-based, responses here, but some defy simple categorization. Community-based or community-managed responses are centred around ‘informal’ fostering, whereby community members assume responsibility for caring for both biological and ‘social’ orphans. This is the norm in a number of countries in sub-Saharan Africa and Asia and has been observed in rural or semi-urban areas where there is little access to services. Religious faith, compassion, community solidarity, reciprocal altruism, concern for society’s well-being and blood ties are all key factors (Williamson 2000; Phiri et al. 2001).

**Community-based care versus institutional care**

While the discussions surrounding scaling up are usually related to community-based responses, externally imposed ‘solutions’ take on a more welfare character. As the impacts of HIV become manifest, there are increasing numbers of institutions such as both registered and unregistered children’s homes and orphanages. In Thailand, the number of HIV-positive children placed in institutions had increased tenfold between 1992 and 1997 (Hennessy 2001). Statutory foster care processes vary, according to whether there is a court or officially appointed figure given the authority to identify, monitor and supervise the foster placement of a child. Guidelines and standards of care act as criteria to determine where to place a child and the failure or success of placement, but their use is inconsistent.

Alternative care options differ from country to country. Typical of South Africa are community family models where up to six children are placed with a foster mother in a home that is purchased and furnished by an external organization or individual (Loening-Voysey and Wilson 2001). The foster mother is paid an allowance and receives foster grants for the children, with periodical assistance from a ‘relief mother’. Siblings are kept together where possible. Community leadership
structures are involved in the process of monitoring, and cluster foster homes are typically run by volunteer women or couples who keep up to six children each and receive foster care grants, material and child care support, as well as health services and income-generation activities. Less common is collective foster care, where faith-based groups of women or couples collectively agree to act as surrogate mothers for children who remain in their own deceased parents’ houses (McKerrow 1996; Loening-Voysey and Wilson 2001).

**Institutional care**

Institutions for children have a long history; early examples were established and maintained by faith-based or missionary groups. For the most part, the growth of institutionalization can be seen as an expedient response to the growing numbers of children in need of care and protection. It may be seen as an easy option for social or child care workers to place children in these institutions, and a growing number of families also ‘place’ their children in orphanages. In many countries, there is no principle of the ‘state as parent’ and no legal requirements governing whom a child can be placed with during their parents’ lives or after their deaths.

One factor that makes orphanages attractive is the perception among some members of impoverished communities that they will provide the food, education, health and other services that the caregivers are unable to offer. A survey by the International Rescue Committee in Rwanda has shown that economic pressure was one of the prime reasons that children were living in institutions (Williamson 2000; Williamson et al. 2001a). Yet this can lead to subtle forms of ‘abuse’ as the raison d’être of the institution is compromised. A study in Zimbabwe showed that 75 per cent of the children in institutions had contactable relatives (Powell 1999); this was echoed by a 1991 study in Uganda which found that half the children in institutions had both parents alive and one quarter had one parent alive (Williamson et al. 2001b). In India’s Mizoram State, 47 per cent of the children in orphanages were placed there after the divorce of their parents. Another 15 per cent were institutionalized because they had been born out of wedlock (Chakraborty et al. 2000).

While they may provide some ‘nurture’, typical institutions do not provide the holistic care that children are entitled to for all-round development. Research has shown that children in institutions lack basic and traditionally accepted social and cultural skills to function in their societies as they have lower levels of educational attainment, have problems adjusting to independence after leaving the orphanage, have more difficulties with relationships, lack parental and basic living skills and sometimes have a misplaced sense of entitlement, without a parallel sense of responsibility (Powell 1999; Wright 1999; Verhoef 2001; Rajkumar 2000; Grainger et al. 2001; Williamson et al. 2001b, International Save the Children Alliance 2003). Children in institutions have tenuous cultural, spiritual and kinship ties with
families, clans and communities. These ties are especially critical in Africa and Asia as they are the mainspring of people’s sense of connectedness, belonging and continuity. They are the basis upon which social, cultural and life skills are attained. Children raised in institutions struggle to be accepted and to fit into traditional rituals and ceremonies as well as contracts and alliance arrangements. The feelings of ostracism these situations engender further adversely affect psychological and emotional well-being. It may also be the case that, after getting used to the trappings of an institution – especially the kind that provides a materially high Western standard of care – children raised in institutions may look down upon their own communities as being inferior (Powell 1999).

A separate critical issue with institutions is cost. In most countries with mature epidemics and an unprecedented growth in the numbers of orphans, it is impossible to accommodate a sufficiently significant number to make an impact. The annual cost of keeping a child in a centre in Rwanda, for example, is approximately $540, plus the cost of donated food (Williamson et al. 2001a). In Eritrea, the cost was estimated at $1,350 per child per year, while in 1990 in the United Republic of Tanzania it cost $649 each for a year, and in Burundi the equivalent figure was $689 (Ainsworth and Rwegalurina 1992; Lusk et al. 2000). In South Africa, statutory residential care was estimated to cost as much as R2,590 ($180) or R3,525 ($245) per child per month with palliative care costs. A 1995 survey in Zimbabwe revealed that the average monthly cost of maintaining a child in an institution was Z$1,058 in the most expensive facility and Z$341 in the least expensive. Rapid inflation would have pushed these figures to Z$3,000 and Z$1,000 respectively. Z$1,000 is about the entire average monthly salary of a typical family in the country.

The costs of setting up institutions also need to be considered. In Zimbabwe, where between a fifth and a third of children are orphans, the capital cost of just one institution was estimated to be Z$25 million. In contrast, a traditional-type family unit for orphans cost Z$500,000 to set up, with monthly running costs of Z$131 per child. It is therefore estimated that institutions are 14 times more expensive than traditional arrangements (Powell 1999). Apart from the costs, the capacity limitations make institutional arrangements illogical for orphans. In Zimbabwe, there are only 41 institutions, accommodating fewer than 3,000 orphans (Powell 1999). Institutions should therefore be the last resort, after family, foster or community care, and in the absence of other models of care being available.

It is sometimes argued that correctly managed institutions can provide emergency temporary care to protect orphans at risk of abuse and that they can help with behavioural and emotional difficulties. However, they are an expensive resource, with an inherent danger of institutionalization, and placements for children should only be used when it is in the child’s best interest and subject to the CRC article of periodic review. During the 1990s, Uganda provided a model for inspecting and
monitoring the use of residential care facilities. The process involved collecting information on institutions and the children in them, followed by legal regulation and policy guidelines, staff training through open distance learning materials, an implemented policy of reunifying children able to return to families, plus inspection and monitoring by the Government.

**Evolving models of community-based care**

Precisely to respond to these problems with institutions, a number of countries have developed alternative models of care. The Civil Affairs Departments of Anhui province and Guangde county in China have been working in partnership with Save the Children UK, embarking on a programme to shift from large-scale institutions to smaller groups of family-type homes, integrated into communities.

Where children are unable to live with their families, they should be settled in environments that approximate as nearly as possible to the family home. In the family-style units in the China programme, children attend nurseries and schools in the community just like other children, girls and boys live in the same unit as siblings and disabled children are not segregated. Communities thus participate in the raising of these children, who are therefore not isolated and learn social and cultural skills and self-reliance.

Support can be given to help prevent families breaking down in the first place, and to allow children to get out of institutions. In Ethiopia, the SKIP project and the Jerusalem Association for Children’s Homes both worked to de-institutionalize children by enabling them to travel to their birthplaces during school holidays to look for their kin. Older adolescents were helped to become independent by developing their own business plans for which they were given small grants, being placed in apprenticeships where they received skills and mentoring, and being given opportunities to attend higher education. As a result of children being reintegrated into their communities, one home was closed (Gebru and Atnafou [n.d.]). SKIP promoted the concept of family-type units where children lived in the same style of housing as other community children, had the same standards of clothing and nutrition, went to the same schools, worshipped in the same faith-based structures and engaged in the same mode of agriculture as their peers in the communities. After eight years, SKIP had reintegrated 98 per cent of the children back into their communities.

Temple boy systems and community care centres have been suggested as other alternative models of care, especially where there is a strong Buddhist tradition. In Cambodia and Thailand, it is traditional for boys to be placed in a temple where they receive an education. This has been suggested as an option for orphaned boys if the faith community could be encouraged to extend the system to such children and actively destigmatize their links to HIV (Brown and Sittitrai 1996). This may
be a critical model in Cambodia, where the genocide of 1975–1979 (killing 1–3 million people) removed many potential grandparent caregivers for the orphans, estimated to number 60,000 at the end of 2001. Without a concerted and widespread response, rates of child abandonment in Cambodia will be unusually high for AIDS-affected populations. Through their own structures and faith-based organizations (FBOs), other faiths could be encouraged to adapt the system (Foster 2004). Such a system, if developed, would need to recognize the situation of girl orphans and monitor the children’s welfare in the long term.

Given the scale of the current and impending orphan crisis and realizing that fostering arrangements will be one of the responses that will be promoted in most low- and middle-income countries, it is important to note that most of these countries still retain legislation, criteria, guidelines and administrative procedures based on Western models. For example, in South Africa, in 1998, the Government introduced child support grants for under-sevens living in impoverished households, with the intent that within five years up to 3 million children would have had access to the grant. After the first year, however, less than 30,000, or a meagre 1 per cent, had been able to receive the grant. This was because of stringent information requirements. Not everyone in rural and impoverished areas had the birth certificates that the authorities demanded (Loening-Voysey and Wilson 2001). Although the situation has improved, the debate has moved the target processes and the legitimacy of using demographic and health, rather than economic, criteria; i.e. targeting orphans rather than the poorest children (Meintjes et al. 2003).

Models of fostering and adoption services developed in the West are by no means universally useful. Adoption requires rigorous legal oversight and assessment procedures and may not be applicable in societies where the extended family considers itself to have responsibility for a relative’s child. Fostering also provides definitional problems, as it is necessary to be clear as to exactly which parental responsibilities are being transferred to the foster parent, and in the case of formal fostering what responsibilities lie with the government social workers and the state. Some fostering schemes were started in countries in political transition in Eastern Europe, intended as alternatives to institutions. They have, however, rarely reduced numbers of children in residential care, but have emerged as a parallel system requiring both fostering allowances and supervision on a long-term basis. In some instances, relatives have refused to care for children when allowances were not forthcoming. Formal fostering on a long-term basis raises many rights issues and may not be the panacea.

In most cases, low- and middle-income and transition countries have not ensured that their social policy keeps pace with their economic reform. In those countries where institutions are the first policy choice for care, state revenues have dwindled to levels where institutions can no longer be supported adequately. The impending huge numbers of orphans will make the situation even more unmanageable if no
alternative models of care are developed. In addition, the minimum standards set for formal foster care and adoption are often too high for the many poor but willing community members. The concept of ‘good enough’ standards appropriate to the local context, norms and traditions of the community in which the child will grow up should be seriously considered in these countries where the numbers of orphans are mind-numbing (Phiri et al. 2001).

Comparing cost-effectiveness and quality of care

Research in South Africa has examined both the quality of care as well as the cost-effectiveness of six models of care for orphans and vulnerable children (Loening-Voysey and Wilson 2001; Desmond and Gow 2001). The six models included: statutory residential care; statutory adoption and foster care; unregistered residential care; home-based care and support types; community-based support structures; and informal fostering or non-statutory foster care. The authors argued that it was imperative to develop a framework for evaluating the quality of service as well as assessing the economic feasibility of each approach. ‘Quality of care’ was defined as ‘care which meets the needs of children in a culturally relevant and acceptable manner and, at the same time, enables them to realize their rights’ (Loening-Voysey and Wilson 2001). The analysis concluded that institutional care was the most expensive and least cost-effective of the models and that community-based care and informal fostering were cheaper and more cost-effective. However, the study also pointed out that the quality of care in family or informal fostering was increasingly being compromised by a distinct lack of, as well as access to, resources. The needs of the orphans being looked after in this manner were therefore not being properly met and their rights were not being recognized.

Table 1. Cost-effectiveness of six models of orphan care in South Africa

<table>
<thead>
<tr>
<th>Model of care</th>
<th>Cost per child care month (Rands)</th>
<th>Cost per minimum standard child care month (Rands)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statutory residential care</td>
<td>2938</td>
<td>2590</td>
</tr>
<tr>
<td></td>
<td>(3873*)</td>
<td>(3525*)</td>
</tr>
<tr>
<td>Statutory adoption and foster care</td>
<td>609</td>
<td>410</td>
</tr>
<tr>
<td>Unregistered residential care</td>
<td>996</td>
<td>957</td>
</tr>
<tr>
<td>Home-based care and support</td>
<td>506</td>
<td>306</td>
</tr>
<tr>
<td>Community-based support structures</td>
<td>**</td>
<td>276</td>
</tr>
<tr>
<td>Informal fostering/ Non-statutory foster care</td>
<td>**</td>
<td>325</td>
</tr>
</tbody>
</table>

Notes: *Including medical costs associated with the child’s HIV-positive status. **Fail to meet material minimum. Source: Desmond and Gow 2001.
Costing exercises are hampered by the fact that there are some aspects of care that are extremely difficult to measure or cost, particularly the affection or love of the carer. It can also be argued that it would be difficult to cost or measure ‘community parenting’ where significant others in the community contribute to the parenting of orphans. There is also a clear discrepancy between the availability of resources in a given context and the realization of children’s rights. As discussed above, a lack of awareness of the rights of children as enshrined in the CRC, as well as difficulties involved in the application of rights-based approaches to policy and programming, remain a serious challenge. The difficulties involved in such a costing review are many, and relate to the following:

- variation in intervention types;
- a tendency to cost specific subcomponents of programmes, such as food or education costs;
- varying definitions of target groups and their vulnerability;
- lack of capacity inventories for different community contexts;
- varying values of resources in different contexts: of land, population density, leadership strength, human resource availability;
- subjective nature of costing human resources and other aspects of ‘social capital’;
- difficulty in quantifying and measuring quality of support given;
- problems with costing the strengthening of health and social service systems.

Within the COPE Programme in Malawi, by July 2000, the District and Community AIDS Coordinating Committees had raised around $20,000 of the $1.6m needed to keep COPE going through to 2001. In other words, only around 1.25 per cent of the total amount needed for the programme was mobilized internally (Williamson and Donahue 2001). This raises the question of the potential for sustainability, as well as the need to better define non-financial resources, since finances are only one component of the social capital generated by the programme structures.

These and other issues are major constraints to reaching universal consensus on costings, and the way forward may be firstly to define support packages per capita/family, and have estimates according to each, using methods employed in health systems management models, or those developed to cost home care structures. Current costings along these lines are being developed by UNICEF and Futures Group International, and the eventual ‘unit costs’ of child care will be vital in ascertaining how much interventions, taken to scale, should cost across varying contexts.

**Orphan support as community development in eastern and southern Africa**

Despite the uncertainties, scaling-up efforts are ongoing. The Uganda Women’s Effort to Save Orphans (UWESCO) has used the model of children’s villages to organize
cluster and community foster care arrangements (chapter 2). The organization gives school and medical costs, assists with food and clothing provision, and organizes training in community-based child care and livelihood support for families with orphans. UWESO uses an approach that enables communities themselves to care for orphans, thus engendering ownership and facilitating sustainability. By the end of 2001, the project had had an impact on over 10,000 orphans, raising income at household level and increasing the nutritional status of the children, as well as improving the quality of shelter in the community.

A further example is provided by the FOCUS project in Zimbabwe. This is a programme of the Family AIDS Caring Trust (FACT). Research on orphan enumeration and community coping mechanisms has been conducted by FACT since 1991. In 1993, the FOCUS programme started by recruiting several volunteers from villages and FBOs throughout the communal farming programme area. The programme emphasized identification and monitoring of vulnerable children through regular household visits; community ownership; keeping children in school; income-generating activities; and volunteer training and motivation.

In the ongoing programme, volunteers are responsible for identifying and visiting orphan households within a two-kilometre radius of their homes. Those considered most vulnerable are allocated priority status on a register and visited at least twice a month. The volunteers identify the unmet basic needs of the households and provide essential material support, including maize seed, fertilizer, food, clothing, blankets and school fees (costing around $2–4 per year). The visits provide emotional and spiritual support, and the volunteers may also offer to bathe the children, sweep the house, fetch firewood or cook. The visits enable the children’s situation to be observed, so that children who are out of school, in emotional distress or being abused are identified and appropriate action can then be taken. The likelihood of abuse, exploitation and maltreatment of orphans lessens in communities where frequent visiting occurs. These visits also enable spiritual activities such as prayer, scripture reading and songs of praise to be shared. Psychosocial support is provided through weekly craft, cultural and sporting activities. Income-generating projects initiated by volunteers include gardening, crocheting, greenhouse horticulture involving mushroom growing, goat keeping, poultry rearing, sewing and knitting. Volunteers who look after orphans in their own homes may receive small amounts of material support (average $11 per annum). Incentives help to keep volunteer drop-out levels very low. They are also involved in advocacy and awareness-raising on orphan support issues (Phiri et al. 2001). By 2000, 178 volunteers were active in the programme, 97 per cent of whom were female. The lack of male volunteers in the programme is an obvious issue of concern and is part of a wider reluctance on the part of males to take on caring roles.
Total programme costs stayed fairly constant at between $20,000 and $30,000 per annum, and approximately 50 per cent of programme expenditure was at community level in the form of material support, volunteer incentives and meeting costs. The annual cost per family was approximately $10, and per vulnerable child $3. The cost per visit was $0.11, while the cost per volunteer was $68. The programme has been replicated within Zimbabwe and in four other countries in Africa.

Good practice learning and dissemination

Capacity building also provides for international learning. The basic concept is that of the ‘living university’. This is an ongoing resource and technical assistance centre for local, national and international visitors. Save the Children US has successfully piloted this concept in Egypt and Viet Nam. The living university is an ongoing social laboratory where an implemented project can be observed and discussed at various stages of implementation. Its ‘campus’ is the key locales of the programme and the ‘faculty’ comprises the key staff members who have been trained as trainers as well as the community members who are implementing the activities. The curriculum is largely the training manuals, constantly evolving and being developed during the course of the implementation of the project. At the local level, the living university locales are principally centres of learning, where community-to-community learning through visiting and collaborative review can take place (Phiri et al. 2001). The living university also provides critical technical assistance and quality control and a framework for monitoring and evaluation to local partners (Hunter 2001).

Addressing the non-material needs of orphans: succession planning and psychosocial support

The psychosocial needs of children affected by HIV and AIDS, especially orphans, are most often neglected in programme design. Most organizations, governments, donors and indeed even CBOs, have felt that the material, economic, nutritional and other physical needs are the most critical, requiring immediate response. However intangible, the psychosocial needs of children are critical – as they have a direct bearing on all the development aspects of a child growing in any context. Psychological wounds might be manifest in different guises including, but not limited to, depression, isolation, aggression, listlessness, attention deficits, nightmares, unresolved guilt and eating disorders.

As parents become sick, children worry about them and about their own future. They do not usually verbalize these feelings, making it difficult to assess whether they have reached closure about the terminal illness or death of their parent(s). They may instead become withdrawn, aggressive, play truant, engage in antisocial
behaviour and be prone to depressive disorders in adult life (Poulter 1997). The children do not just lose parents, they also suffer a loss of parenting – which entails a loss of connectedness, a bond, a sense of trust and continuity. Sibling separation also exacerbates feelings of isolation. In a Ugandan study, two thirds of older children in affected households are separated from at least some of their siblings (Gilborn 2000). Children’s needs for security from all aspects of economic want (based on their families’ capacities and context) cannot be separated from their psychosocial and emotional needs. Some commentators and researchers have termed these as ‘psycho-economic needs’.2

Often children are also not told about the progression of the parent’s disease or the cause of the parent’s death. Overtly, this is to protect the child from trauma and pain and to conform to cultural norms regarding discussion of death and loss. Some experts feel that it is important to disclose the status of the parent’s illness to children aged seven and over as they are mature enough to understand the finality of death and are aware of HIV and AIDS because of what they hear and learn at school and in the community. It is argued that having this information may help to protect children from contracting the disease, since they sometimes care for the parents. Others argue that disclosing the information only makes life harder for children. Yet the decision should rest with the parents. Because of the strong and deep emotions involved, and the deep-rooted traditional sensitivities, HIV-positive parents find it very difficult to disclose their status to their children. But children do sense what is going on around them, even if it is not discussed with them or expressly articulated and this can make them more anxious and stressed. Research in the Kagera region of the United Republic of Tanzania concluded that children whose parents had talked to them about dying appreciated the opportunity to share time and listen to their advice about how to do things after the parents’ death (UNAIDS 2001). Similarly, in Uganda, 69 per cent of a sample of affected children, whose parents had discussed their HIV status with them, thought that parents’ openness about their status was positive (Gilborn 2000; Gilborn et al. 2001).

In the early 1990s, the National Association of Women Living With AIDS in Uganda (NACWOLA) adopted the Barnardo’s-initiated idea of a memory book, a journal of facts and memories for children who face imminent loss or separation from a parent. It is an attempt to keep alive the memories and milestones in the child’s and family’s life. Connecting the past, present and the future, the memory book or box helps the child keep a sense of continuity, belonging and rootedness. It provides an opportunity to talk about HIV and may facilitate disclosure of parental (or even child) serostatus, sometimes with the direct help of counsellors (Alidri 2001).

Planning who will look after the child(ren) after the prospective death of one or both parents is also a crucial element of the programme. Parents or guardians discuss, with the participation of the child(ren), the person who will be their caregiver
or parent after the death of the AIDS-affected parent. In around 40 per cent of cases, the person chosen is an uncle or aunt (Gilborn 2000). Besides surrogate parenting, mothers also discuss other options, identifying someone who would be considered the primary caregiver and others who could play significant roles in the child’s life. This mirrors reality, where children are parented not just by the one biological mother and father, but also by relatives, neighbours and other adults. The Memory Project will also initiate projects to address children’s and widows’ inheritance rights and other legal issues.

The Humuliza project in the United Republic of Tanzania shows that schools and teachers are central to the emotional development of children affected by AIDS (UNAIDS 2001). Teacher training that responds to the psychosocial needs of affected children has become a critical policy and programme response. Teachers were sensitized to identify the needs of children and communicate with them. The teachers in turn advocate response to these needs with politicians and traditional leaders. The teachers have also created a fund for orphaned children in their schools or communities, which helps to buy essential school supplies. They contribute TZ shillings 200 ($0.26) every month from their own salaries (UNAIDS 2001).

A working definition of psychosocial programming should be embedded in the psychological and social dimensions of a specific culture. Generally, the main aim of psychosocial programming is to protect children from the accumulation of stressful events; to enhance the capacities of families and communities to respond to the psychosocial needs of children as well as to help children rebuild a sense of normalcy and continuity. The goals should ideally be to implement programmes that, among other outcomes, enable children to form secure attachments with caregivers, meaningful relationships with their peers, and strong social and cultural ties and connections, while developing their self-esteem and key competencies and being given access to economic opportunities and a sense of hope for the future (Duncan et al. 2001).

Programming should be based on the strengths of the community (Cook 1998), rather than focusing on its negative aspects. Critical to this is identification of protective factors – features of the external and internal environment that facilitate resilience in the children and their community. What are the enduring or transient social supports and characteristics that enable these to emerge? What makes some children thrive despite the poverty and in spite of the death or incapacitation of their parents? How do strong attachments, a sense of trust and security, adaptability, independence and peer relationships help?

In the United States, the importance of a consistent connection to a primary caregiver (in particular the biological father) has been well documented as being one of the main determinants of risk outcomes in adolescents. Children without such a connection are prone to early sexual experience, violence, greater involvement
in risk activities and a negative social outlook (Kirby 1999; Resnick et al. 1997; Blum and Reinhart 2000; Jessor et al. 1998).

Psychosocial support is implicit in support programmes. Microcredit programmes for women, youth skills training, and employment creation are critical to economic needs but also fundamental to psychosocial health. These programmes may help to reduce stress related to worry about the future economic status, and in the case of adolescents, the programmes increase their self-esteem and provide opportunities for peer relationships and social skills (Duncan et al. 2001). Structure, predictability and stimulation contribute to a strong sense of connection for children, and rites of passage, ritualized routines, recreational activities, traditional games, stories, legends, myths, song, dance, movement, sports all contribute to this end. As parents die from AIDS-related illnesses, these connections are increasingly under threat. The implications of this psychological deficit are not yet manifested, but commentators point to increased levels of violence, deviancy, adult depressive disorders and rather tenuous links to ‘terrorism’.

**HIV in the context of poverty – the challenge of resource mobilization and flows**

It has been suggested that HIV will be the main obstacle to reaching national poverty reduction targets and the UN Millennium Development Goals. Hitherto, internationally, most policy responses have been focused on prevention, control and treatment. There has been little on mitigation, even less specifically on orphans (Loewenson and Whiteside 2001). Yet HIV and its impacts cause and deepen poverty. The epidemic is directly and indirectly linked to a host of negative outcomes that include reduced social sector spending, giving rise to a lack of access to affordable health care and prevention services; lower education status; falling household per capita income, increased spending on medicines and funerals; lost productivity, disrupted farming cycles and systems; increased dependency ratios, worse gender inequalities, increased number of orphans, street children, crime, and sex work. These outcomes inevitably and unavoidably give rise to perverse household risk management strategies, including the sale of land and assets (Cohen 1999; Hunter 2000a; Loewenson and Whiteside 2001; Adeyi et al. 2001; see also chapter 7).

In response to the challenge, the World Bank’s Enhanced Social Protection Programme in Zimbabwe aims to reach vulnerable children. One component of the programme is the Basic Education Assistance Module (BEAM). The programme, which was expected to begin operation in 12 districts, waives school and examination fees in order to reduce the number of needy children dropping out of school because of economic constraints. Broad-based and inclusive school selection committees, comprising members with knowledge of the socioeconomic situations of the communities in
which they live, are responsible for identifying the children most in need of assistance. The funds for fees and levies go directly to the accounts of the schools each semester, while the stipend element goes to local post office savings banks. Eligible children can withdraw part of this stipend at the beginning of the school year to cover expenses for uniforms, travel and other school supplies, and are allowed to withdraw the remainder if they satisfy minimum attendance criteria. A system of monitoring and evaluation with periodic participatory assessments has been established. The programme is expected to reach approximately 426,000 children at both primary and secondary schools throughout the country and will cost $6.8 million, or an annual cost of $16 per child (Subbarao et al. 2001). It would be ideal if the guidelines in question could be developed with active input from the communities concerned, using their own criteria or index for vulnerability (Phiri et al. 2001).

Another component of the programme is the Children in Extremely Difficult Circumstances element (CEDC), the objective of which is to intensify various forms of assistance to children by strengthening the communities’ capacity to respond to their needs. Child welfare fora have been established to assist communities with training and grants to CBOs and NGOs working with children and their families. Two other components are public works, which will supplement incomes of poor households through temporary employment, and secondly capacity building for planning, implementation and monitoring of the institutions (World Bank 2000).

Similarly, the Social Investment Fund in Zimbabwe and the Social Action Fund in Malawi have developed modules and training programmes that are offered to each community as part of the outreach process. Grants are now being made available in tandem with technical assistance, monitoring and evaluation support.

There is a need, however, for these programmes to demonstrate credibility. The programmes need to ensure effective targeting of the vulnerable, have adequate implementation capacity, and allow genuine participation by communities and children. Questions of sustainability are also paramount.

Given the interrelationship of poverty and HIV, it has been suggested that the heavily indebted poor countries debt initiative (HIPC) provides an opportunity for an unprecedented and significant mobilization of resources. These are the resources to mitigate the impacts of HIV, facilitate multi-partner and multisectoral coordination and collaboration, and allow for scaling up of the ‘best’ practices in response to the pandemic. Indeed, a critical challenge for country teams working on poverty reduction strategy papers (PRSPs) is to include HIV as a central part of the overall poverty reduction effort. Adeyi et al. (2001) suggest that, as part of the HIPC monitoring conditions, the budgetary savings from debt relief could be earmarked and allocated to the HIV programmes through poverty action funds, national development funds or microprojects in order to reach local public and community institutions. In high-prevalence countries, it is estimated that a minimum of $1.50–2.00 per capita
is needed for a solid programme. The savings would constitute an important financial and political investment by the government and thus also prove its political commitment and will. It is imperative that the relationship between poverty and HIV should be flagged and the analysis should be used as an advocacy tool to make the case for HIV within the strategic plan. Only a few countries to date, however, have seized the opportunity in a thorough manner (Adeyi et al. 2001; Bonnel et al. 2004). This is a missed opportunity, sad but indicative of the gaps in strategic planning, policy formulation, implementation, management and programming.

**Resources to base: channelling resources to the frontlines**

The frontlines, meaning those affected by, and responding to, the epidemic, are households, community members, families, various grassroots organizations and faith-based initiatives. However, even collectively, they do not have the economic means to manage the needed response adequately, given the pervasive poverty in these communities and the increasing numbers of orphans. It is therefore important that internal and external resources are mobilized to assist. The challenge, however, is to ensure that such external resources do reach the communities. In the past, international organizations’ efforts to get resources to the communities have been beset by problems of poor targeting, insignificant impact and the extremely low levels of resources (in proportionate terms) actually reaching the targets (Williamson et al. 2001b). At the same time, we have to be careful that organizations, however well meaning, do not undermine communities’ ownership of activities by overwhelming them with resources right at the beginning of the mobilization process, thus creating the impression and expectation that the whole problem will be solved by the external agency providing the money. More often than not, that agency will only be there for two or three years. Large injections of external resources are possibly damaging to ongoing ‘development’ efforts, and a careful balance needs to be struck. Community action cannot be mobilized and sustained by providing resources as a carrot for motivation. Funding should come in tandem with capacity building, geared to the establishment of structures to strengthen absorption, accountability and democratic principles (Phiri et al. 2001).

**Mobilizing political will and the creation of frameworks for policy and programme implementation**

Most affected countries have been charged with lacking political will and commitment. There have been concerted calls for the mobilization of high-level leadership as one of the critical elements in an expanded and effective response to the needs of orphans and children affected by HIV and AIDS. Concerted, active, high-visibility advocacy in all arenas of involvement, including the local, district, national and international, is critical.

The June 2001 UN Declaration of Commitment on HIV/AIDS acknowledges a
strong focus on children infected and affected by HIV, especially those indirectly affected. The governments of the world have signed this commitment and are now accountable for its implementation. There are a number of specific laws, policies and practices that are likely to contribute significantly to improving the lives of affected children. These include:

- Policies and laws to uphold the property rights of orphans and widows in case of the death of their husband and father.
- Free primary school education, with waiver of school fees and subsidies for other school costs for orphans and other vulnerable children.
- Recognition of community schools, with provision of financial and technical support for their establishment and development.
- Gender-sensitive policies, including the waiver of school uniforms for girls and the revision of policies expelling pregnant girls from school.
- Elimination of violence against women (inheritance property expropriation has also been defined as violence against women).
- Support for, and endorsement of, community-based care for orphans, rather than institutions.
- Promoting and supporting good governance within decentralization.
- Provision of clean water and sanitation, as well as more water points, to reduce time spent by women collecting water.
- Development of female economic empowerment activities (credit and other microfinance programmes).
- Female literacy programmes.
- Food security programmes.
- Intercropping practices to reduce weeding time and promotion of high-yielding, less labour-intensive, drought-resistant crops.
- Promotion of natural pest management, thus reducing expenses.
- Improvement of access to land, capital and draught power.
- Well-targeted health insurance – e.g. prepayment schemes for health services, such as letting people pay in kind after they harvest.
- Development of efficient stoves to reduce time women spend collecting firewood.
- Preventive health care to reduce morbidity and mortality.

(Hunter 2000; Phiri 2001; Foster 2001; Loewenson and Whiteside 2001).
Decentralization is the dominant political process within which the response to orphans and children affected by HIV and AIDS is evolving. This could facilitate resource flow to the frontline as well as community empowerment, but only if local officials are accountable to the citizenry. Administrative and financial measures need to include political power sharing, accountability, transparency and real participation by the citizenry and civil society. Really autonomous local control will achieve more benefits than merely assigning figurative responsibility to local government, while substantive programme and resource control remains with central government (Van Sant 2000). Local government is closer to the communities themselves, and is better placed to work with CBOs and NGOs. Communities also have easier access to the decision- and policy-making processes if they are closer to them.

Strengthened local (district) government departments can coordinate activities of local organizations by monitoring and evaluating responses to support orphans. There is also the role of providing technical assistance, engaging in advocacy, implementing targeted income transfers, facilitating local economic growth, and leading poverty reduction programmes. Local government must involve the local citizenry in the design, implementation and evaluation of the responses to AIDS, ensuring that these are implemented by local organizations and that they are transparent and accountable.

The primary constraint remains the disconnect between policies and the laws on the one hand and community participation, awareness and mobilization on the other. There is also disconnection between policies and legal instruments and the perceptions, practices, knowledge, capacities, capabilities and resources of the population. This is one area that external change agents need to address urgently (Smart 2001).

**Conclusions**

The programme and policy challenges highlighted here are only some of the difficulties facing those tasked with designing or facilitating responses to the epidemic. The synergy needed between community-rooted responses and international and national political will is slowly emerging but is still fundamentally absent. The rhetoric of the UN Declaration of Commitment on HIV/AIDS is not matched by efforts to make such proclamations a reality. Meanwhile, on the ground, responses to the epidemic continue to evolve, mostly hidden from the eyes and ears of researchers and documentation experts.

There is no one size fits all. Different communities, depending on their specific needs and prevailing national and local contexts, may require or call for a set of specific responses. There is no widely accepted model of response, but principles and strategies are agreed upon. These must evolve further to better define the vulnerabilities of affected children within communities and the meanings of rights-based
approaches through their application in different contexts. Policy priorities relate primarily to resources, and the balance between community-mobilized resources and external financing and intervention. This balance will vary from place to place and current operational research can provide an understanding of economic realities to be combined with the emerging ethical and principle-based ethos of programmers.

Addressing the psychosocial welfare elements of orphans and children in affected communities is now a matter of urgency. The cycle of infection will be exacerbated if young people grow up in environments where mental ill health is rife, combined with feelings of isolation, despair and social disenfranchisement. The responses required are in themselves not complex, but are needed on such an unprecedented scale that we are only starting to comprehend the implications. While constraints remain in the form of chronic and deepening poverty, capacity limitations and political indifference at all levels, the challenges we face have never been greater.

**References and Bibliography**


Notes

1 Authors’ note. The bulk of this chapter was written in 2001. Since then, there has been a great deal of research, which has helped to develop understanding of the situation and responses. A number of key events have also taken place, most notably (a) the development of national plans of action for orphans and children made vulnerable by HIV and AIDS in 16 countries across sub-Saharan Africa, signifying a realization of political will and (b) the increasing funding being allocated to this area of work, especially from the US, UK, Dutch and Scandinavian Governments. While these initiatives are welcome, the policy response challenge remains daunting.

2 Geoff Foster, 2001 – Electronic forum on psychosocial programming Think Tank.

3 Personal communications with Sian Long and Changu Mannathoko.
AIDS, Public Policy and Child Well-Being

This study addresses one of the greatest challenges of our time: the damage caused by HIV and AIDS to the well-being of children and families. With 38.6 million people affected by HIV in 2006, with HIV prevalence at antenatal clinics exceeding 40 per cent in areas of Botswana and KwaZulu-Natal, with nationwide adult prevalence in excess of the critical threshold of 20 per cent in several countries, and with the prospect of a rapid spread of the disease in large swathes of India and China, the future of child well-being is seriously threatened. Certainly, in the 50 or so countries affected by the disease, the Millennium Development Goals in the field of child survival, education, poverty and basic rights will be missed, often by a large margin.