Economic & Social Affairs

AIDS and the Family:

Policy Options for a Crisis in Family Capital

By Mark A. Belsey

United Nations

ST/ESA/288

Department of Economic and Social Affairs

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New York, 2005

DESA

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ST/ESA/288

UNITED NATIONS PUBLICATION
Sales No. E.06.IV.1

ISBN 92-1-130247-1

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Preface

HIV and AIDS take a profound toll on families. When a family member becomes sick or dies, everyone in the family suffers. HIV/AIDS disrupts the family structure in an irreversible and devastating way. Older people, particularly older women, are put in the position of caring for the sick, the dying and the children orphaned by HIV/AIDS. And children and young girls are often forced to assume adult responsibilities well beyond their years, leaving them highly vulnerable to discrimination, child labour or other forms of exploitative behaviour and, in turn, to HIV infection.

Minimizing the impact of HIV/AIDS on family well-being constitutes an immense challenge. It is also one of the most pressing challenges of our time, faced by families, extended families, communities and Governments around the world. Clearly, we must do all we can to help the family remain resilient. A strong and supportive family is one of the first lines of defence against HIV/AIDS. The family is also often the only safety net, playing a critical role in determining how well individuals and communities cope with AIDS and its consequences.

That is why the United Nations General Assembly Special Session on HIV/AIDS, held in 2001, recognized the important role played by the family in prevention, care and support. It called on Governments to develop or strengthen strategies, policies and programmes that recognize the contribution of the family in reducing vulnerability and coping with the impact of the disease.

The purpose of *AIDS and the Family: Policy Options for a Crisis in Family Capital* is to contribute to this development and strengthening process. It addresses the issues and challenges of HIV/AIDS from a family perspective, using rich sources of information and data to focus particularly on the region of sub-Saharan Africa. The framework used to develop this family perspective is the concept of family capital. This concept, with its three major components of family relationships, resources and resilience, not only provides an enabling framework with which the devastating effects of HIV/AIDS can be addressed from a family perspective. It also serves as a comprehensive and analytical framework from which numerous family policy implications are derived and presented in order to preserve and strengthen families as they face the HIV/AIDS epidemic.

The author of *AIDS and the Family* is Mark A. Belsey, M.D. Dr. Belsey is a retired staff member of the World Health Organization. The United Nations Department of Economic and Social Affairs hired Dr. Belsey as a consultant for a brief period of time to prepare a basic overview background document on AIDS and its effects on the family for the United Nations General Assembly. From this simple beginning, Dr. Belsey volunteered and donated, without receiving any additional payment, an extraordinary amount of time, effort and work over several years into taking the original background paper and expanding and transforming it into a much larger empirical and analytical research project. Dr. Belsey's dedication and hard work in carrying out this project led to the development, research and writing of this publication. We are extremely grateful to Dr. Belsey for the result.

Johan Schöivinck
Director
Division for Social Policy and Development

Foreword

AIDS and the Family began five years ago as a background document for the United Nations General Assembly discussions on the occasion of the Tenth Anniversary of the International Year of the Family. Intended as short overview in support of the activities of United Nations bodies and non-governmental organizations (NGOs), it was gradually expanded to include a review and analysis of the rapidly growing body of information, knowledge and international experience surrounding the HIV/AIDS epidemic, with full advantage taken of the opportunities for secondary research in the age of the Internet. As the text evolved into a manuscript nearly 10 times its original length, a critical assessment of the data revealed discrepancies between the empirical results, on the one hand, and popular beliefs and political rhetoric, on the other hand. What also became apparent was the absence of suitable indicators for estimating the numbers and proportions of families currently and newly affected by the epidemic. In addition, there was no conceptual model for the interaction of HIV/AIDS and the family from which to derive a more precise understanding of the current and likely future impact of the epidemic on the family and its functions.

The genesis of *AIDS and the Family* may be found in United Nations General Assembly resolution 44/82 of 8 December 1989, which proclaimed 1994 the International Year of the Family, and in the well-structured, inclusive and ongoing collaboration of the more than 20 agencies and organizations of the United Nations system with the international NGO networks addressing family issues. A series of Ad Hoc Inter-Agency Meetings on the International Year of the Family served as the forum for this collaboration, where the widely diverse problems facing families were initially acknowledged. It became apparent in the course of the collaboration that the groups of families with which each of the participating agencies and organizations were particularly concerned were often the same families—namely those requiring capacity-building to meet what was first perceived as a somewhat disorderly collection of needs deriving from various social, economic and ecological circumstances. It was ultimately recognized that while particular areas of concern relevant to the family were reflected in sectoral indicators (including those relating to mortality, reproductive health, education, employment, and sources and levels of income), there were no overall family-specific indicators that might provide a more accurate, comprehensive picture. In examining HIV/AIDS in relation to family structures and functions, and in exploring the relationship between families and the various sectors and institutions that provide resources to meet their needs, the author initially retained the approach taken by the Ad Hoc Inter-Agency group, assessing family resilience in terms of social capital; eventually, however, the concept of family capital was developed and adopted as a framework for identifying the challenges and evaluating the impact of HIV/AIDS on the family.

The original draft included a model for estimating the total numbers of families and the numbers and proportions of families affected by HIV/AIDS in each country based on national Demographic and Health Surveys and UNICEF Multiple Indicator Cluster Surveys available by the fall of 2003, and on the UNAIDS *2002 Report on the Global HIV/AIDS Epidemic*. However, just before the final editing of the publication was to begin, the UNAIDS *2004 Report* was issued, providing a revision of the 2001 data and new data for 2003 based on an improved model of the epidemic.

While the issue of HIV/AIDS and the family was addressed in the context of the International Year of the Family in 1994, and in follow-up resolutions adopted by the United Nations General Assembly and the World Health Assembly, little action was taken in the succeeding years, other than a series of research studies initiated by the Food and Agricultural

Organization of the United Nations and its later collaboration with UNAIDS on a study entitled *Sustainable Agricultural/Rural Development and Vulnerability to the AIDS Epidemic*. It is only recently, with the United Nations General Assembly Special Session on HIV/AIDS in June 2001 and the Tenth Anniversary of the International Year of the Family in December 2004, that steps are being taken to promote both formal and ad hoc inter-agency collaboration and activities focused on HIV/AIDS and the family.

It is hoped that this publication will facilitate follow-up of the issues it raises. Efforts should begin with a more systematic examination of the family in the context of economic and social development, in part through the establishment and assessment of family-relevant development indicators. In addition, steps should be taken to reactivate collaboration within the United Nations system, as reflected in a recent resolution of the World Health Assembly (WHA57.11), which notes the "devastating effects of the HIV/AIDS pandemic on families" and calls for the Director General to "work closely with the United Nations Department of Economic and Social Affairs and other relevant organizations of the United Nations system ... on issues related to families", as well as with NGOs and research and development institutions.

Acknowledgements

I would like to thank Terri Lore for her indispensable help in editing the manuscript, John Bongaarts for his comments on the family household model and Joanne Csete for her critical review of an earlier version of the document.

I would also like to give thanks to Amr Ghaleb for having initiated this project, and to Odile Frank, Robert Huber and Eric Olson of the United Nations Department of Economic and Social Affairs, and to Luz Maria Saavedra and José Tatad of the United Nations Statistical Library.

My wife Ann, and our three daughters and five grandchildren have given depth and resonance to my concept of family capital."

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ABBREVIATIONS AND EXPLANATORY NOTES

AIDS	acquired immunodeficiency syndrome
AIM	AIDS Impact Model
CDC	Centers for Disease Control and Prevention (United States)
DHS	Demographic and Health Survey(s)
FAO	Food and Agriculture Organization of the United Nations
FDA	Food and Drug Administration (United States)
FOCUS	Families, Orphans and Children under Stress (Zimbabwe)
GDP	gross domestic product
GNI	gross national income
HIV	human immunodeficiency virus
HPI	human poverty index
HSV-2	herpes simplex virus type 2
IDU	injecting drug user
MICS	Multiple Indicator Cluster Survey(s)
MTCT	mother-to-child transmission
MSM	men who have sex with men
NGO	non-governmental organization
STD	sexually transmitted disease
TASO	The AIDS Support Organization (Uganda)
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNICEF	United Nations Children's Fund
UNFPA	United Nations Population Fund
USAID	United States Agency for International Development
VCT	voluntary counselling and [HIV] testing
WHO	World Health Organization
Z$	Zimbabwe dollars

The following symbols have been used in tables and text throughout the publication:

Two dots (..) indicate that data are not available or are not separately reported.

A dash (—) indicates that the amount is nil or negligible.

A hyphen (-) indicates that the item is not applicable.

A minus sign (-) indicates a deficit or decrease, except as indicated.

Parentheses ( ) in tables may indicate a deficit/decrease or a small number relative to others in the same context.

ABBREVIATIONS AND EXPLANATORY NOTES (*continued*)

A full stop (.) is used to indicate decimals.

A slash (/) between years indicates a crop year, school year or financial year, for example, 1990/91.*

Use of a hyphen (-) between years, for example, 1990-1991, signifies the full period involved, including the beginning and end years.*

References to "dollars" ($) are to United States dollars, unless otherwise stated.

Details and percentages do not necessarily add to totals, because of rounding.

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the United Nations Secretariat concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries.

The designation of country groups in the text and tables is intended solely for statistical or analytical convenience and does not necessarily express a judgement about the stage reached by a particular country or area in the development process.

The term "country" as used in the text of this publication also refers, as appropriate, to territories or areas.

Sub-Saharan Africa includes all of Africa except Algeria, Egypt, the Libyan Arab Jamahiriya, Morocco and Tunisia.

Bibliographical and other references have, wherever possible, been verified.

* It should be noted that the titles of a number of national Demographic and Health Surveys used for the present analysis imply coverage of two years (for example, 1990-1991) when the period in question may actually include only parts of each year.

There would be no society without families,
but equally there would be no families
if society did not already exist.

Claude Lévi-Strauss, *A History of the Family*

CHAPTER 1
AN INTRODUCTORY OVERVIEW

HIV/AIDS is a family disease. The family network and family capital are major factors influencing the capacity of families to cope with the disease and its consequences. Families affected by the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) may be considered "healthy" or "unhealthy", depending on the strength of the bonds within the family network and the effectiveness with which family capital continues to be accumulated, used and protected for the benefit of infected and uninfected family members.

The HIV/AIDS epidemic has traditionally been perceived in terms of vulnerable groups and/or individual risk behaviours. When the issue of AIDS and the family has been addressed, it has typically been in the context of children and families; parental death, orphans and foster care; and the deterioration of family economic circumstances.[1] Recent developments indicate, however, that a broader and more comprehensive view is beginning to emerge. In the summer of 2001, the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) recognized the importance of family support in the prevention of HIV/AIDS.[2] A number of reasons have been cited for assigning high priority to social policy issues as they relate to AIDS and the family, including the following:

- In most settings, infection occurs in the context of the family, including sexual relationships, pregnancy, delivery and breastfeeding;
- The family shares in, and tends to bear most of the responsibility for, the care and support of persons living with AIDS;
- The stigmatization, discrimination and social exclusion* associated with
- HIV/AIDS are suffered by both infected individuals and their families.[3]

A fourth reason for focusing on HIV/AIDS from a family perspective is that the epidemic has a profound, often permanent, generally adverse, and frequently intergenerational impact on the family's structure, functioning and well-being, even long after all HIV-infected members of the family have died. Families may be reconfigured and headed by grandparents, children or more distant relatives—or may disintegrate altogether, as is the case when orphaned children are placed in foster care. Surviving members suffer a loss of income, wealth, and social and family capital.†

The present publication assesses the impact of HIV/AIDS on the family, focusing on issues that have not heretofore been systematically addressed, including changes in family structure, functions, and intra- and extra-family relationships and roles. The findings and conclusions form the basis for the policy options and programmatic responses proposed in the last chapter. These recommendations are aimed at ameliorating the adverse impact of the epidemic by facilitating the protection and support of affected families and enabling them to function and fulfil their roles and responsibilities.

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* Defined as "the inability of our society to keep all groups and individuals within reach of what we expect as a society and the tendency to push vulnerables and difficult individuals into the least popular places"; see A. Power, "Social exclusion", *Royal Society of Arts Journal*, vol. 2, No. 4 (2000), pp. 47-51, as noted in G. Watt, "Policies to tackle social exclusion", *British Medical Journal*, vol. 323, No. 7.306 (28 July 2001), pp. 175-176.

† Social capital consists of the social networks of mutual trust and generalized reciprocity within communities and institutions (adapted from T. Welsh and M. Pringle, "Social capital", *British Medical Journal*, vol. 323, No. 7,306 [28 July 2001], pp. 177-178). To this is added the concept of "family capital", which has three dimensions: relationships and the family network; family resources (knowledge, skills and material resources); and resilience. Family capital, which is similar to and has much in common with social capital, is explored in greater detail in chapter 2, and at the end of this chapter in the context of the framework for reviewing the impact of HIV/AIDS on the family.

Box 1. Early ideas on AIDS and the family

"In the early years of the epidemic in Africa, Jonathan Mann, the first co-ordinator of WHO's worldwide AIDS programme, commented ... that African societies had some advantages over Western industrial countries in that AIDS patients would not be isolated, and that their families would look after them. Thus, in Africa, the condition of the AIDS sufferer will be better appreciated if it is looked at within the framework of the family."

Statements such as these, made on the basis of popular assumptions rather than documentation, often prove erroneous as more research data and in-depth analysis become available. This phenomenon is especially prevalent among politicians and health authorities that have lost contact with "the field".

Source: J.K. Anarfi, "The condition and care of AIDS victims in Ghana: AIDS sufferers and their relations", *Health Transition Review*, vol. 5, supplement (1995), pp. 253-263.

1.1 A brief overview of HIV/AIDS

In the summer of 1981, the first cases of what is now known as AIDS were reported in the United States of America, and in 1984 HIV was identified and established as its cause. A laboratory test developed and licensed by the United States Food and Drug Administration (FDA) in 1985 permitted the identification of apparently healthy HIV-infected persons and the screening of blood (used for transfusions) and blood products, and facilitated a better understanding of the epidemiology of HIV infection and AIDS.[4] The same year, the Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO) convened the First International Conference on AIDS. The early establishment of standardized case definitions and increased awareness of the new syndrome facilitated the official reporting of cases to WHO; between 1985 and 1993 the number of reported cases rose from 15,202 to more than 300,000. In 1987 the FDA approved the first antiretroviral agent for the treatment of AIDS. From a historical perspective, the rates of scientific discovery and technological development were unprecedented.

In 1982, Uganda became the first African country to identify cases of AIDS; however, the situation differed from that in the United States in that individuals of all ages and from all walks of life appeared to be affected.[5] The presence of HIV is now felt around the globe, though the burden of the epidemic is borne primarily by resource-poor developing countries, where the disease is spread mainly through heterosexual intercourse. Currently, 95 per cent of all infections occur in developing countries, with sub-Saharan Africa and South-East Asia accounting for the largest regional shares.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) and WHO have estimated that 35.7 million adults and 2.1 million children under the age of 15, or a total of 37.8 million people worldwide, were living with HIV/AIDS by the end of 2003. Nearly 3 million AIDS-related deaths and 5 million new infections were estimated to have occurred that year.[6]

As the rapidly expanding body of knowledge and extraordinary technological advances made it possible to address the medical dimension of HIV/AIDS, it became apparent that there were actually three epidemics:*

* It should be noted that the three epidemics are non-sequential (characterized by varying degrees of overlap) and have occurred at different times in the

- The epidemic of HIV infection that progressed silently for over a decade;
- The epidemic of AIDS and AIDS-related illnesses;
- The epidemic of fear, perhaps more accurately described as fear and silence.*

An understanding of each of the three epidemics is critical for the development of policies, strategies and programmes not only to address the disease itself, but also to protect and support families affected by HIV/AIDS by ensuring their security, integrity and effective functioning.

Although HIV was initially identified as a disease concentrated mainly among homosexual men, the most common mode of transmission in a majority of countries and at the global level is heterosexual intercourse. The presence in individuals and populations of other sexually transmitted diseases (STDs) increases both vulnerability to and transmissibility of HIV.[7] Other modes of transmission of public health concern include transfusions of infected blood or blood products; the sharing or reuse of contaminated needles by injecting drug users (IDUs) or for therapeutic procedures; and mother-to-child transmission (MTCT) in utero, at birth, or through breast milk. The implications and risks associated with the modalities of transmission, such as the impact of breastfeeding on the health and survival of both mothers and infants, are still being debated and investigated.[8] While intensive research has led to remarkable breakthroughs over the past two decades, a comprehensive understanding of HIV/AIDS remains elusive.

HIV causes a chronic infection that in most individuals begins with an acute syndrome followed by an asymptomatic stage. Data from developed countries indicate that the disease, left untreated, progresses in young adults (aged 15-24) and older adults (aged 45-54) over a median of 11 and 7.7 years respectively to the late stage referred to as AIDS† (see annex I).[9] Virus replication following the initial infection is rapid and extensive. New anti-HIV drugs given in potent combination regimens have demonstrated impressive efficacy by both clinical and laboratory measures, and have provided evidence that drugs can suppress HIV replication and disease manifestations. Initial doubts about the capacity of individuals to follow antiretroviral therapy regimens, and of health systems in developing countries to provide and supervise treatment programmes, have been resolved as technical developments have allowed the simplification of therapy formulation and regimens, and as relevant field research has been carried out.

Research suggests that the pattern and rate of progression from untreated HIV infection to AIDS and death in developing countries do not parallel those in developed countries. Many infectious diseases and nutritional disorders that have been eliminated or controlled or have become readily treatable in developed countries still abound in less developed areas, so differences in the course of HIV might be expected as well. Various studies highlighting the situation in Uganda provide some insight in this regard. Prospective community-based studies undertaken in rural parts of the country revealed that the risk of dying was 20 times higher for those who were or became HIV-

affected countries and regions. For the sake of convenience, the three epidemics will be referred to as the "HIV epidemic", "the AIDS epidemic", and "the epidemic of fear" when addressed separately.

* The third epidemic was originally described in terms of "the social difficulties to which [the first two epidemics] give rise" (R. Frankenberg, "Social and cultural aspects of the prevention of the three epidemics [HIV infection, AIDS and counterproductive societal reaction to them]", in *The Global Impact of AIDS: Proceedings of the First International Conference on the Global Impact of AIDS*, A.F. Fleming and others, eds. [New York, Alan R. Liss, Inc., 1988], pp. 191-199). With the evolution of the social context, it is now believed that fear and silence better characterize the third epidemic.

† Unless otherwise noted, references to the various stages of HIV/AIDS are based on the WHO staging system, detailed in annex I.

positive than for those who were HIV-negative.[10] Disease progression associated with HIV infection was more rapid than that encountered in developed countries. The median time from the development of AIDS to death in the Uganda studies was 9.3 months.[11] Over half of the HIV-positive individuals who had at least one of six conditions or symptoms* died within 10 months. However, the prevalence of these symptoms was lower than 10 per cent among those who were HIV-positive, and symptoms were not necessarily a strong predictor of early death. In longitudinal studies in Uganda in which all individuals were seen every 10 months, 40.5 per cent of those whose death was subsequently attributed to HIV infection had not had symptoms of illness in the preceding 10 months, and among those with symptoms, only 9.5 per cent met the full clinical definition of AIDS (see annex I).

Fewer than 10 per cent of adult women in developing countries are likely to have been tested for HIV, with many of those tested not subsequently informed of their HIV status, so it is not surprising that communities and authorities only start to take notice when the number of funerals or the demand for coffins or burial sites rises dramatically. In some developing countries, as noted above, there are many HIV-positive individuals who either pass rapidly through or never exhibit the obvious signs and symptoms of AIDS or AIDS-related illnesses. Thus, death may arrive unexpectedly and be attributed by the family to causes other than AIDS.[10]

The lack of understanding of the HIV epidemic among leaders and policy makers in many countries—and the consequent failure to take ameliorative action—has probably contributed to the impending disaster facing families and communities. In several countries in which HIV prevalence has risen to very high levels in a short period of time, national authorities and leaders have failed to acknowledge the importance or appreciate the magnitude of the epidemic owing to the initial absence of massive numbers of deaths or large numbers of AIDS patients filling hospital beds. Hospital bed occupancy increases and HIV-associated deaths accelerate as an epidemic matures owing to the increased average duration of HIV infection and the fact that HIV-positive subjects may, on average, be at a later stage of infection and thus have a higher probability of dying.[10] As the epidemic progresses in any particular setting, deaths resulting from HIV/AIDS are likely to constitute an increasing proportion of total mortality and to become a significant factor in reducing overall life expectancy.

Generally, the full extent and implications of HIV/AIDS are not brought home to national policy makers until well into the epidemic, when health-care demands far exceed the available services, and when leaders in other sectors, such as education and agriculture, begin to express serious concerns. Some communities and leaders may eventually come to appreciate the impact of the AIDS epidemic on family structure, functions and resources. Early identification, acknowledgement and response is the key; there must be recognition of the potential of the epidemic and the need for anticipatory or pre-emptive action—which requires an understanding of the basic epidemiological pattern. Many countries have been in denial about the stage they have reached and are either unaware of the appropriate response or unwilling to take the action necessary to address the challenges associated with that and subsequent stages. In sub-Saharan Africa, one of the regions hardest hit by the epidemic, only one country recognized the early signs and acknowledged the potential consequences of the failure to act. Even then, it has taken this country 15 to 20 years of extensive research, substantial grass-roots community involvement, and strong, consistent and continuing political, technical and resource support at the national and international levels to turn the epidemic around.

The third epidemic—that of fear—which technically is more containable, in theory, unfortunately fuels the first two. At all levels of

*Weight loss, prolonged diarrhoea, prolonged cough, thrush, Kaposi's sarcoma or tuberculosis.

society the epidemic of fear and silence has impeded efforts to address HIV/AIDS-related issues in a sensitive, effective and timely fashion. This mindset has woven its way into the fabric of very diverse cultures, affecting both HIV-infected and uninfected individuals, weakening the cultural cohesion of communities and professionals alike, and denying individuals, families and communities the knowledge, skills and tools they need to protect themselves. Political and moral authorities bear much of the responsibility for the inattention and inappropriate responses to the epidemic; many Governments spent far too long (and some still remain) in a state of denial or self-righteous hostility,[12] despite mounting evidence that HIV/AIDS constitutes a global and often local threat to security at a number of different levels.

When countries and communities first become aware of HIV/AIDS in their own settings, the response is typically one of multiple-level dissociation; those who have contracted the disease are stigmatized and often shunned, and restrictive and discriminatory laws and regulations are imposed against them. During the five years following the initial identification of the epidemic in the United States, children with HIV/AIDS were not permitted to attend school in several states, and arsonists burned down the home of one family; in 1990, immigration policy barred the entry of HIV-positive individuals wishing to attend the Sixth International Conference on AIDS in San Francisco. Other countries have gone so far as to isolate those who are HIV-positive in special camps. It has not been unusual for government authorities, in particular those linked to tourism, defence or other "sensitive" sectors, to ignore the evidence and publicly deny that their countries have an HIV/AIDS problem. By the year 2000, the third epidemic had reached such proportions that the theme of the Thirteenth International AIDS Conference, held in Durban, South Africa, was "Break the Silence".

Silence, denial and stigmatization in the culturally sensitive area of human sexuality are important contributors to the epidemic but predate AIDS by decades. The values and attitudes reflected in such responses have been manifested in the unwillingness and/or inability of countries to deal with adolescent sexuality, and in their tendency to maintain a narrow focus on the technical aspects of contraception in family planning programmes rather than seeking to understand and apply emerging scientific knowledge in the field of human sexuality or to convey to the public the knowledge and skills required to negotiate equitable and sexually responsible human relationships. The global HIV/AIDS pandemic has forced Governments and national and international institutions and organizations to start placing these issues on their policy and programme agendas, often in the face of fierce resistance.

Before the Secretary-General of the United Nations submitted his report on all aspects of HIV/AIDS to UNGASS,[13] the response to the pandemic consisted mainly of prevention and control efforts largely shaped by the definition of HIV/AIDS as a problem of individual behaviour. Based on epidemiological data about individual risk behaviours, the public health strategy developed in the mid-1980s was aimed at providing information and education designed to induce and sustain changes in behaviour. Other activities approved under this strategy included the provision of health and social services, the distribution of condoms, HIV testing and counselling, and drug abuse treatment and needle exchange programmes. The approach was consolidated by the WHO Global Programme on AIDS into a three-part model for HIV prevention (encompassing education, services and technology) and a strategy for the protection of human rights, in particular advocacy and action to ensure non-discrimination towards those with HIV and AIDS.

The relationship between AIDS and poverty is complex. It is widely acknowledged that AIDS causes or accelerates the descent of massive numbers of individuals, families and communities into poverty, undermines development, and contributes to widespread and worsening poverty at the societal level.[14] However, this does not mean that AIDS is

essentially a disease of the poor and disadvantaged. In many developing countries in which relevant studies have been undertaken, it is often within the more educated, upwardly mobile and professional groups that HIV/AIDS first strikes.[10, 15] In other words, during the early stages of an epidemic, the disease frequently claims those most critically placed in establishing and maintaining the infrastructure and institutions for social and economic development.

The Secretary-General has noted that while HIV/AIDS continues to be an important health issue, it "has evolved into a complex social and economic emergency". The epidemic "changes family composition and the way communities operate, affecting food security and destabilizing traditional support systems. ... It destroys social capital ... leading to still more widespread and extreme poverty. In short, AIDS has become a major challenge" jeopardizing national and international security.[13]

1.2 The rationale for a review and analysis of AIDS and the family

The affirmation in the Universal Declaration of Human Rights* that "the family is the natural and fundamental group unit of society and is entitled to protection by society and the State" is reiterated in the International Covenant on Civil and Political Rights,† the International Covenant on Economic, Social and Cultural Rights,‡ and other regional and international instruments. "By making protection of the family a fundamental right which must be guaranteed by States, the international community reaffirms the principle that the family takes precedence over society and the State, because without the family there would be neither society nor State."[16]

AIDS affects the structure, functioning and very survival of the family on such a scale as to constitute a threat to society. In areas stricken by HIV/AIDS, traditional definitions of the family and concepts of "normal" family functioning may be challenged.[17] Many of the demographic, social, economic and security consequences of the epidemic derive from or are amplified by its adverse impact on the families of individuals who are living with or have died from the disease; therefore, it is not possible to address these issues or concerns without attending to the needs of such families.

The impact of the three epidemics on the structure, functions and role of the family as such has received only limited attention. Even less has been said about policy options for supporting, protecting and strengthening the family in the face of these epidemics. Analysis and measurement of the epidemic in terms of the structure and functioning of families affected by HIV/AIDS would provide important indicators of the developmental vulnerability of communities. Such indicators would be necessary to identify and evaluate policies aimed at strengthening the capacity of families and communities in the mobilization of social and family capital to protect their own development. Finally, a review of AIDS and the family could serve to reinforce those HIV/AIDS-specific policies that would also strengthen the capacity of families to function well in spite of the ongoing challenges and relentless pressures they face.

HIV/AIDS first affects intrafamily communication and relations. Once a person's HIV-positive status or progression to AIDS has been confirmed, he or she must contend with the issue of disclosure, which "has profound and disruptive effects upon other family members and their capacity for problem-solving. This disruption, while expressed differently, occurs in all cultures. It is evident in traditional, extended families; small, nuclear and basically urban family units; and alternative, or affiliated, family structures. The extent and duration of family disruption are influenced by history and strength of family bonds, previous experiences with illness and loss, and attitudes about HIV and AIDS. The last is a most important determinant. Shame about HIV infection and AIDS, and

* Article 16, para. 3.

† Article 23, para. 1.

‡ Article 10, para. 1.

concern about the reactions of other people, are virtually universal reactions."[18]

The adverse impact of HIV/AIDS on the family is noted in the Secretary-General's report[13] and recognized in the UNGASS Declaration of Commitment on HIV/AIDS.[2] Both the report and the Declaration acknowledge the importance of the family at three levels: in contributing to HIV/AIDS prevention; in supporting and caring for those with HIV/AIDS; and in ameliorating the effects of the epidemic on the community and society. In each case, emphasis is placed on services that may be provided by, rather than for, the family; the observation that families affected by HIV and AIDS typically face a range of challenges beyond those relating directly to the disease—and may be in desperate need of assistance themselves—has largely been ignored.[19]

The impact of the epidemic on families varies according to the following:

- The magnitude and duration of the epidemic in a country;
- The epidemiological pattern of HIV/AIDS among different cultures and groups;
- The structure and functions of the family in a particular setting.

Families, especially in the developing world, are prevented from responding effectively to the epidemic by the lack of HIV testing and counselling services, by the apparent fact that a relatively low proportion of persons living with HIV in developing countries exhibit clear symptoms of AIDS before death, and by the depth and pervasiveness of the epidemic of fear and silence. Even when HIV status is determined, the individuals tested are not always informed of the results by the health service or other responsible authorities. When confirmation of HIV seropositivity is provided, family responses are characterized by essential weaknesses common to all cultures and settings. These include the family's unwillingness or inability to establish open and effective intrafamily communication, to negotiate supporting roles, to build and maintain healthy relationships, and to develop plans or strategies for meeting the future needs of the family and its members.

While families may display a certain degree of vulnerability or weakness in the face of the epidemic, the limited research available suggests that the majority cope satisfactorily—in spite of the enormous material, social and psychological costs.[1] One critical ingredient for effective coping appears to be a dependable family network that extends beyond the immediate family household and serves as a substantial reservoir of family capital. Maintaining family strength, cohesion and resilience must constitute a priority; anecdotal media reports, which serve as a rough measure of the evolving social impact of HIV/AIDS, indicate that the family support system is becoming increasingly frayed and eroded as the epidemic progresses.

Cultural traditions and gender are important factors affecting the course of and response to HIV/AIDS in communities. While women are at greater biological risk for HIV infection, a large part of the increasing burden the epidemic places on them results from their being unprepared and lacking the power to negotiate sexual relationships and roles within the family. Data from Demographic and Health Surveys and other research indicate that in the developing world, the vast majority of women newly infected with HIV are monogamous and have acquired the disease from their partners. Furthermore, almost invariably, females are the caregivers for people living with AIDS. In developing countries they typically bear the triple burden of caring for children, older persons and those with AIDS. Often they are financially responsible for their families' survival, and girl children and older women often find themselves assuming the role of head of household. Girls from poor families are at higher risk of exploitation, often sexual in nature, as they struggle to increase the family income.[13]

In a number of countries, the marked increase in mortality among economically active adults has resulted in significant losses of skilled and unskilled labour in key sectors, to the extent that social and economic development achieved

in the 1960s and 1970s is being undermined and in some cases reversed. "Young, highly productive adults are dying at the peak of their output",[20] which is having a considerable impact on the economy in many countries. In some areas the epidemic is having a noticeable and increasing effect on population growth and death rates. In countries with adult HIV/AIDS prevalence rates of over 20 per cent—namely, Botswana, Lesotho, Namibia, South Africa, Zambia and Zimbabwe—the death rate is projected to be 112 per cent higher during the period 2000-2005, and the population 19 per cent lower in 2015, than would be the case without AIDS.[21]

The impact of HIV/AIDS on families—not only those with HIV-positive members but all families within a community—is mediated as well by its impact on specific sectors. For example, AIDS takes its toll on health services and is directly linked to the loss of staff and difficulties in recruiting qualified new staff, increased material costs, and the deterioration of the supporting health infrastructure. The diversion of limited resources to deal with HIV/AIDS has raised concerns about the ability of the public health establishment to address other family health needs. Affected families are less able to send their children to school, but a more pervasive problem is the loss of teachers to AIDS, which undermines the capacity of school systems to meet the expectations of all families. In a similar vein, while the surviving children of affected families often lack the skills and knowledge to engage in agriculture, animal husbandry or other rural-based production, deaths within such groups as agricultural extension workers undermine the development support relied upon by all families.

Hitherto, there has been no systematic cross-cultural examination of the impact of AIDS on the family. With the recently accumulated data from such sources as the national Demographic and Health Surveys (DHS), the Multiple Indicator Cluster Surveys (MICS) published by the United Nations Children's Fund (UNICEF), and updated UNAIDS models and estimates for the HIV/AIDS epidemic, it is now possible to undertake a comparative analysis of the scope of the impact of HIV/AIDS on the family, and to examine some of the factors associated with variations in the prevalence and incidence of HIV infection and families affected by HIV/AIDS. Indicators on discriminatory attitudes and the living arrangements of children and data on numbers of sexual partners among married women and men in the DHS and MICS have been used in the present analysis as surrogate family-specific indicators, with which it has been possible to test a number of hypotheses relating HIV/AIDS to family-specific issues and factors such as family structures and living arrangements, education, intrafamily communication, and sexual behaviour.*

The family must become a focus for research and policy review. While many of the issues pertinent to AIDS and the family are sector-specific, family-relevant policies must be examined from a cross-sectoral and intersectoral perspective. They must be seen not only in the social, cultural and economic contexts of each society, but also in relation to the stage of development of the family and the evolving pattern of the epidemic. For most of the world, the responsibility for care and support rests with the immediate family and other relations, and in all settings the family or household is a critical interface between the individual and society. If individuals are shunned or ostracized, either socially or economically, their families bear the brunt of the stigma and its consequences.[22]

UNGASS and the Declaration of Commitment have placed the family on the international HIV/AIDS agenda. It remains to be seen whether this constitutes a negotiated compromise to rhetoric, thus perpetuating the use of "the family" as a lightning rod in unscientific and sterile debates in which gender and family represent opposing ideological poles, or whether the Secretary-General's report is

* See annex II for the list of sub-Saharan African countries included in the assessment and the national DHS and MICS used as sources of data in the present publication.

taken seriously by all countries, and HIV/AIDS and the family are seen to constitute a genuine priority for research, policy review and development.

1.3 A framework for addressing family policy issues and HIV/AIDS

Regardless of the impact of the most recent commitments and strategies for preventing HIV and addressing the needs of persons living with HIV/AIDS, the effect of the epidemic on families and the family as a social institution will persist long into the future. Because family stability and security is of critical importance, it is imperative that steps be taken to address the complex relationship between HIV/AIDS and family policy issues, with the ultimate aim of achieving full integration. A suitable framework and an intersectoral perspective are essential in this ongoing endeavour. A family-HIV/AIDS framework must focus on family needs per se, and not merely on the family's role in preventing HIV transmission and caring for those with AIDS.

The framework provided herein derives from an examination and analysis of the interaction of the three HIV/AIDS epidemics with each of the three elements of family capital (family relationships, resources and resilience). This approach takes the following into account:

- The epidemiological and trend analysis of HIV/AIDS, with particular notice taken of the numbers and characteristics of families affected by HIV/AIDS;
- The structure and functions of the family and intrafamily relations—particularly as they affect and are affected by HIV/AIDS;
- The economic, social and cultural contexts and the specific impact of HIV/AIDS in those contexts.

The framework and supporting information provided in this publication are intended to demonstrate the following:

- The family provides an additional perspective from which to measure the full impact and multiplier effect of the epidemic;
- For the vast majority of those living with HIV/AIDS, the family is the main unit of care and support;
- HIV/AIDS has an adverse impact on many family functions, though the nature and extent of this impact varies according to the age or stage of development of the family members and to the stage reached in the family life cycle;
- The analysis of the implications of the relationship between HIV/AIDS and the family takes into account not only the family household, but also the family network and the concept of family capital;
- The indicators of the impact of AIDS on the family may serve as additional indicators of community vulnerability.

A framework for examining the functions and tasks of the family in different settings is essential in assessing possible family policy options in response to the HIV/AIDS epidemic. There are many models used to describe the functions and tasks of families, most of them derived from the experiences of industrialized countries and based on the nuclear family and a family life-cycle approach.[23] The ways in which these models can be adapted to situations in other countries and cultures are explored later in the publication.

The use of a framework will facilitate the identification of first- and second-order family policy issues. First-order policy issues are those that directly affect the integrity, functioning and well-being of the family. A family may be considered healthy, in the broadest sense, despite the presence of severely ill family members. Such families are described as resilient, drawing upon the strength of the relationships within, and range of resources accessible to, the family, and able to cope in situations of adversity. Identifying the elements of family capital in a particular culture and determining whether there are any facilitating policy elements should be a priority for any work undertaken on AIDS and the family. Second-order policy issues are those that arise predominantly from among the priorities of

other sectors but have a profound impact on the resilience, functioning and coping capacity of families facing the AIDS crisis.

The current review raises a number of family-focused research issues that are of potential interest or relevance to various programmes, agencies and organizations of the United Nations system. The respective areas of concern should be given careful consideration by these bodies, with priorities assigned and suitable recommendations formulated.

The further follow-up of the recent Tenth Anniversary of the International Year of the Family, the designated plenary meeting of the United Nations General Assembly on the family in December 2004, and the present publication all provide a critical opportunity to highlight the importance of incorporating relevant family policy issues in national AIDS programmes, to promote collaboration on family issues within the United Nations system, and to stimulate methodological research on indicators as well as the monitoring and analysis of nationally and locally relevant issues relating to AIDS and the family. The framework, approaches and methods of analysis used in this publication may serve as a starting point for these processes.

CHAPTER 2
THE FAMILY: CHANGING STRUCTURES AND FUNCTIONS

2.1 Defining the family

In spite of its varied and changing forms, the family remains the dominant and natural grouping in society providing emotional and material support essential to the growth and well-being of its members. Beyond this generalization, the concept of family is not easy to define. The United Nations recognizes that various forms of the family exist in different social, cultural, legal and political contexts, and that it is therefore impossible to assign the concept a standard definition.* Definitions may also vary depending on the nature and availability of relevant data, on the individuals involved in the collection and application of such data, and on the purposes for which the data are to be used.

In examining the impact of AIDS on the family it is necessary to consider, and if possible reconcile, the various family models used by demographers, sociologists and anthropologists.

Demographers and epidemiologists typically use the household as the unit of study and analysis in census and survey data. It is important to understand, however, that the family and the household are not necessarily synonymous.[24] When household data include the relationship of the head of the household to other household residents, it is possible to distinguish between family and non-family households. With census data thus collected, the United States Census Bureau defines a family as a "group of two people or more (one of whom is the householder) related by birth, marriage, or adoption and residing together; all such people (including related subfamily members) are considered as members of one family." This definition, generally used by demographers and economists, applies to what is also referred to as the "residential family". "The average size of all residential families regardless of type or complexity is close to the average household size because very few members are not related to the head, especially in the Near East/North Africa and Asia (< 1 per cent), but also in sub-Saharan Africa (2 per cent) and Latin America (2 per cent). Clearly, non-family household members represent only a tiny minority of household members in these developing countries."[25]

Others have attempted to incorporate both traditional and contemporary perspectives into a working definition of the family, asserting that "family members are individuals who by birth, adoption, marriage, or declared commitment share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need."[26]

From the perspective of behavioural and social scientists, "families have never fit nicely into any single model. 'Family' may refer to people linked by marriage or kinship or to people claiming descent from common ancestors in a lineage, tribe or clan. People may form and extend families by adopting and fostering children, defining non-relatives as family, or establishing consensual partnerships."[27]

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* The United Nations Human Rights Committee has noted that "the concept of the family may differ in some respects from State to State, and even from region to region within a State, and that it is therefore not possible to give the concept a standard definition. However, the Committee emphasizes that, when a group of persons is regarded as a family under the legislation and practice of a State, it must be given the protection referred to in article 23 [of the International Covenant on Civil and Political Rights]." (United Nations, "General comment 19 [39] on article 23 of the International Covenant on Civil and Political Rights" [CCPR/C/21/Rev.1/Add.2.], para. 2; comment adopted at the 1,002nd meeting [39th session] of the Human Rights Committee, 1990).

The residential family or family household definition does not take into account non-resident family members with whom there is likely to be important social and economic interaction.[25] While the non-resident family member is difficult to accommodate in comparative statistical analysis or modelling, such a person is likely to represent a significant factor in assessing family capital, and may be an important contributor to the resilience or vulnerability of families affected by HIV/AIDS. Resident and non-resident family members make up the family network, which may be intergenerational, horizontal, or a combination of the two. The responsibilities and obligations of non-resident family members may be culturally or legally defined, and may involve the provision of care or support for those within the network affected by HIV/AIDS (individuals with the disease and their immediate families). Specific duties often include, but are not limited to, economic support, inheritance or care of the widow (referred to as levirate* in areas of Africa), assistance in the education of children, and the foster-care placement of orphans within the family network.

2.2 The relationship between HIV/AIDS and family structure, functions and stages of development

For statistical purposes, the family household will serve as the operational definition of the family in this publication.† Operational definitions of families affected by HIV/AIDS and family networks will be provided below. Estimates of family households have been derived from national DHS and MICS data.‡ Particular attention has been given to those data sets that include information on childcare living arrangements. In the present and subsequent chapters, reference may be made to other family structures as they relate to the relevant policy options for preventing or mitigating the adverse impact of HIV/AIDS on the family.

2.2.1 Family structure

The structure and functions of the family change as it passes through the different stages of the family life cycle, and as it adapts to new economic, technological, cultural, political and environmental circumstances. The extended or joint family was the norm in pre-industrial societies, serving as the unit of production in economies based on subsistence and labour-intensive agriculture. The structure and functions of the family and its internal relationships are greatly affected by the increased mobility and migration of individuals and families as a consequence of economic change and development, the demand for labour, and perceptions of enhanced social and economic opportunities.

Three perspectives on family structure provide useful reference points in analyzing the AIDS/family relationship. The subsections below draw a distinction between family structures based on family households, family structures based on family networks, and family structures characterized by childcare arrangements. Immediate care provision, decision-making and resource allocations occur in the family household. When the profound consequences of AIDS are experienced, demands may be made on the family network.

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* Levirate is examined in greater detail in chapter 8.

† Although the DHS data sets contain information on family relationships, it is only recently that analysis of these data has been initiated (see J. Bongaarts, "Household size and composition in the developing world in the 1990s", *Population Studies*, vol. 55 [2001], pp. 263-279). In order to establish an approximation of family households, single-person households have been subtracted from the total number of households, based on the assumption that in the countries being considered multiple-person households of unrelated individuals represent a very small fraction of "true" family households.

‡ Estimating the number of family households involved subtracting single-person households from total households, based on the assumption that those in single-person households are either not members of any family household or are non-resident family members of already enumerated family households. In most developing countries multiple-person non-family households are uncommon and need not be taken into account in estimating family households.

Family structures defined according to childcare considerations provide a useful indicator of situations in which one or both parents have died, or in which the child lives with another family in the network in order to obtain an education or acquire specific skills and/or training.

(a) Family structures based on the family household

Household-based family structures include the following:

- Nuclear families: legal marital unions, common-law unions, visiting unions (stable), single parents, and families reconstituted as a result of remarriage after death or divorce;
- Enlarged, extended and multiple-family households: vertical households (stem family), horizontal households (extended family of siblings), combinations of the above or multiple-family-relation households (including kinship and tribal arrangements whereby family members share a common compound), and polygamous households.

In many countries and cultures, several forms of family households are common and coexist. In the West Indies, for example, three types of unions are recognized:

- Married union (a couple living together and legally married);
- Common-law union (a couple living together but not legally married);
- Visiting union (a couple neither living together nor legally married).[28]

Another dimension of the relationship between the family structure and AIDS includes the marital mobility of the family as reflected in serial marriages. "Serial marriages can be defined as the participation in a sequence of regular partnerships or unions. By this definition, males in polygamous unions are involved in the practice of serial marriages in that they go through the formation of regular unions more than once in their lifetime and are often involved in more than one such union at a time. In the case of females, serial marriage takes the form of transition from first to second and subsequent unions within a monogamous or polygamous framework."[29] Men who are in "monogamous" marriages but engage in concurrent or casual unions outside of marriage tend to be at greater risk of HIV infection than those in serial unions—with two exceptions: though levirate and polygamy are classified as serial unions, those engaging in such practices are also at a higher risk of contracting the disease. Even adolescent schoolchildren (both male and female) from polygamous families are more likely than those from monogamous families to engage in sexual activity.[30] While polygamy under normal circumstances does not affect the risk of child mortality, it does accentuate such a risk among the children of HIV-positive mothers in a polygynous union owing to the diversion of resources away from these children.[31]

Family size (the number of adults and children) is significantly smaller when the head of the household is a woman. Spouses are present in nearly all family households headed by a male, but the same is true for no more than 10 per cent of female-headed family households.[25] Single-parent households headed by women are not uncommon and appear to be increasing in many areas of the world. However, they represent a very heterogeneous family structure, particularly with respect to family functions, resources, and bonds with a non-resident spouse. Such households may truly be headed by a single parent owing to divorce or to spousal death or desertion, or they may be households in which the spouse is a medium- or long-term economic migrant but still functions as part of the family, particularly through the provision of remittances to the resident spouse and/or other family members.

The decline in family size over the past several decades has been well documented in both developed and developing countries. However, a recent analysis of data from nine countries suggests that hidden within the decline

may be a small—but in terms of family capital and resources significant—increase in the number of adult family household members.[25] Such findings, if borne out in further studies, would represent an important consideration in the development of family policies relevant to HIV/AIDS.

(b) Family structures based on family networks

Family networks extend beyond the common household or compound. They are found in all regions and most societies, and membership in such networks generally involves formal or informal responsibilities and obligations beyond the family household. Family networks may be composed of kinship, tribal or other family groupings. Such networks are extended through marriage, and may be attenuated by divorce. They may be characterized in the same manner as extended families, that is, as horizontal, vertical, or a combination of the two, or even as part of a polygamous system. In their horizontal dimension they are seen in terms of siblings and cousins, and vertically in terms of parents, offspring, uncles, aunts, nieces, nephews, and other relatives at least one generation removed. Included among family network indicators might be estimates of surviving siblings and of the survivorship of parents and parents' siblings.

Family networks are a particularly important part of any system of care and support for families affected by HIV/AIDS. There is wide variation in the degree to which family obligations and responsibilities extend outward from the "biological" centre of the nuclear family and follow either the maternal or paternal lineage. Defining the nature and extent of intra-network relationships may represent an important contribution to the development of strategies for HIV/AIDS prevention as well as for care and support. It has been noted that "the traditional African family ... is a network of people, most of whom are connected by kin or blood relationships, termed the clanship system. Patterns of family treatment and care are deeply embedded in this wider kinship system."[32] Social change has undermined traditional patterns of care and cooperation within this context; nonetheless, the clanship system remains relatively solid and "could become the locus of AIDS activity designed to ensure the well-being and continuity of the family, where its leadership undertakes to sustain, to reorganize, or to create wholly new families or structures among populations being devastated by AIDS."[32]

Similar types of family network structures and patterns of functioning are found in other regions of the world. A 1995 summary of the General Family Survey in Thailand indicated that 25 per cent of family households had at least one parent (the mother or father of the household head or his/her partner) in residence, and 80 per cent had relatives living nearby. Problems were frequently discussed with parents and other elders. Even those families that did not have parents living with them generally provided economic support and sought them out for advice.[33]

(c) Family structures classified according to childcare arrangements

Family structures characterized by childcare arrangements have received a substantial amount of media and public attention because of the large numbers of children orphaned by HIV/AIDS.* The standard definition used in reference to such children identifies their condition but does not sufficiently convey the impact of the disease on the family. The loss of either parent to AIDS has a dramatic effect on the structure and functioning of the family, but the nature of the impact differs enormously depending on which parent dies. A father's death has the greatest impact on the family

* UNAIDS currently defines children orphaned by HIV/AIDS as those under the age of 17 who have lost one or both parents to AIDS or AIDS-related illnesses; however, it still uses the age group 15-49 to estimate the numbers of adults living with HIV. UNAIDS cautions against using the term "AIDS orphans", noting that this term stigmatizes those children and labels them as HIV-positive, regardless of their serostatus.

income and, by extension, on family resources, food security, and the education of children. The death of a mother has an immediate effect on the caring functions within a family and, depending on her economic participation, may also have an impact on food security. Surviving children are affected in different ways depending on their age and sex.

To facilitate analysis within this context, caretaking arrangements should be classified according to whether the child or children live with and are cared for by both parents, the mother only, the father only, or neither parent. Simultaneously, the family household can be characterized in terms of whether either, neither or both of the parents are alive.*

The development of locally relevant family policy options in response to the HIV/AIDS epidemic requires current data or reasonable estimates and projections relating to family households broken down in terms of precisely defined childcare arrangements. Among non-parent-headed family households in this category, the major types of childcare arrangements and family structures include the following:

- Kinship-based foster care;
- Non-kinship-based foster care;
- Kinship-based adoption;
- Non-kinship-based adoption;
- "Grandparentalized" families grandparent-headed family households);
- "Parentalized" child-headed families (child-headed family households).

Depending on the existence, application and precedence of judicial or customary law, it may be important to distinguish between the various forms of "legal" adoption and foster-care arrangements. These types of childcare arrangements are affected by such considerations as the age of majority, inheritance laws, and the custodianship of orphaned children, and all of this has a bearing on the structure and integrity of the family and household.

In many countries and cultures, the option of kinship-based foster care allows rural families to situate their children in towns or larger urban settings that may offer enhanced educational or training opportunities. Such arrangements are generally beneficial; however, physical, economic or sexual exploitation occurs with sufficient frequency to be noted in the local media and to be of concern to child-welfare advocates in many countries.

In communities in which HIV/AIDS prevalence is high, family households headed by grandparents are increasingly likely to include the children of several of their offspring. Under normal circumstances, the allocation of children to either the maternal or paternal line within kinship families is culturally designated. However, with the marked increase in the number of children orphaned by AIDS, these patterns have changed.

2.2.2 Stages of family development

Every family goes through stages of development, often collectively referred to as the family life cycle. The developmental process for most nuclear families includes the formation of a new family through marriage or a consensual union; childbearing, child-rearing and childcare; the completion of childbearing; the departure of children; and the dissolution of the union with the death of one of the partners. For nuclear families that ultimately have children, the family life cycle in its simplest form includes the following six stages:

- Formation;
- Extension;
- Completed extension;
- Contraction;
- Completed contraction;
- Dissolution.

* Many of the more recent DHS and MICS have included modules that use a form of this classification, but without any reference to the cause of death of either parent.

For the extended family this cycle is perpetuated up to the time that the extended family structure ceases to exist. The family-life-cycle model can be adapted and modified to reflect variations in the dependence and independence of family members within and between societies. Depending on the purposes for and settings in which the model is applied, the number of stages can be either reduced or expanded. For example, additional stages or sub-stages may be inserted to reflect the ages of children or events such as retirement.

To accommodate the effects of HIV/AIDS on the family structure and life cycle, the model would require further adaptation to include variations such as the following:

- Reconstituted families, including those resulting from remarriage following divorce or the death of a spouse;
- Re-established, skipped-generation families in which grandparents (or other older relatives) are the primary caregivers for dependent children.

Passages from one phase or sub-phase of the family life cycle to another are characteristically assigned major importance by families and are often marked by celebrations or periods of mourning. Events such as marriage, birth, the completion of education cycles, and death are usually accompanied by specific family rituals, ceremonies and/or gatherings. Nearly all such events have implications for family capital, in terms of both bonding and the accumulation or distribution of material or monetary resources.

HIV/AIDS has an impact on these life-cycle transitions, and may produce a family crisis unrelated to or even incongruous with a particular stage of the cycle. For example, the discovery that a pregnant woman or newborn is HIV-positive is likely to produce enormous stress within a family at a time when its members should be experiencing great joy. At the other end of the family life cycle, AIDS may suddenly catapult grandparents (usually grandmothers) back to an earlier stage in the cycle as they become responsible for their orphaned grandchildren. AIDS-related illnesses lead to a decrease in family assets and the attenuation of children's education, and therefore have a direct and dramatic impact on family capital. The death of an economically active adult from AIDS not only reduces family income, but also imposes an undue burden on the immediate family and family network in the form of time and liquid asset costs.

2.2.3 Family functions and tasks

Family structures and functions and intrafamily roles and relationships are in a constant state of flux owing to the following:

- Long-term historical shifts in technology, modalities of production, population migration, the population structure and urbanization;
- The short- and medium-term consequences of natural and man-made disasters and conflicts, and of economic and social disruption and opportunities.

In all societies throughout history, families have had productive, reproductive and protective functions. In pre-industrial societies there was great concordance between social and economic functions; the family served as the major unit of economic production but also assumed many of the health-care, developmental and socialization functions; involvement of the immediate community was secondary. Specific functions evolve to ensure that the family's essential needs are met; the responsibilities undertaken within this framework include the following:

- The provision of food and shelter;
- The allocation of tasks, including those linked to gender;
- The distribution of family goods and resources;
- Decisions on the health and other care needs of family members;
- The socialization of future generations;
- Decisions on the education and training of the young;
- The perpetuation of cultural traditions and rituals;

- The intergenerational transmission of moral, ethical and/or religious values.

Families may confer status and prestige on their members, provide them with protection, and take on religious and recreational functions. In many African[32] and Asian[33] cultures and elsewhere, elders retain a prominent place in the social organization of family and kinship functions, exercising particular authority in matters relating to birth and death through their involvement with funerals and burials, the inheritance of widows, succession issues, and other such exigencies within the family and clan.[32]

In many traditional societies, women are the primary health-care providers at the nuclear family level. In such settings, illness is perceived not as an isolated phenomenon but rather within the context of the local culture and belief system, and decisions on health care involve assessing whether an illness has an immediate or natural cause, often easily understood, or a supernatural cause, with the latter necessitating divination.[32]

As societies have become progressively more urbanized and complex, the family and society have increasingly shared responsibility for tasks and functions traditionally performed within the family setting, such as work (in terms of the locus of production), education and childcare. In this modified milieu the emphasis of family functions has shifted, with the personal development of individual family members assuming greater importance. In some cultures this is reflected in the higher levels of independence and autonomy among children. In societies that have retained their strong cultural roots or are still in transition, greater emphasis is placed, in child development and education, on the values of interdependence and social harmony. In the more modern settings, the stages of family development may be characterized[23] in terms of the following:

- Integrative functions (three categories):
  - Sexual behaviour; moral behaviour;
  - Supportive/affective behaviour; socialization of self and/or young;
  - Conflict and conflict resolution.
- Task functions (two categories):
  - Filtering and/or cushioning function between individual and society;
  - Economic functions; political/legal functions.

Even as some of the functions of the family have been transferred to or shared with other institutions and sectors, so has the nature and extent of the family's primacy undergone a shift, as reflected in its new and critical role as the first-level guarantor of the human rights of family members, in particular those who are most vulnerable and dependent upon the family's functions. This family function is explicitly set forth in the principles and articles of the Convention on the Rights of the Child, but is also inherent in other international human rights instruments.

2.3 Social and family capital*

The concept of social capital was originally defined as "the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual ... recognition."[34] The term refers to those social relationships that allow individuals access to resources possessed by their associates, and to the amount and quality of those resources [35] upon which people depend for social, economic and emotional support. Social capital strengthens the capacity of individuals and social groups to function and attain their goals and objectives.[36] The concept has reportedly

* Family capital is a new conceptual tool that is being introduced in this publication to achieve a better understanding of the relationship between AIDS and the family. The three components of family capital— relationships, resources and resilience—have been clearly identified as factors affecting the ability of families to cope with the three epidemics. Because there is also some interaction between relationships, resources and resilience in the family's response to HIV/AIDS, family capital is believed to provide a unifying conceptual framework.

been useful in identifying the more proximate variables accounting for the correlations of mortality and morbidity with such social and economic variables as income, social class, ethnicity and similar factors.[37, 38] Social capital appears to be an important contributor to the resilience of individuals in the face of social disorganization or adversity.

Those elements of social capital that may be characterized in terms of the bonds, resources, and characteristics of resilience found within families can be considered either a subset of social capital or, if recognized as being of sufficient importance, a separate entity: family capital.

The elements of family capital can be characterized in terms of relationships, resources, and that which constitutes resilience. The relationship component represents the foundation of this concept; in its absence there is no family capital, and individuals are left to draw upon other sources of social capital or their own resources. The relationship component is largely defined by a combination of demographic variables and cultural characteristics that articulate levels of kinship, particularly in traditional societies. In urban settings, and especially in industrialized societies with a plurality of cultures, the relationship component of family capital is either defined by the family itself—at a minimum identified as the nuclear family but more often as the multigenerational nuclear family—or established by the particular culture within the plural society. The family network is at the core of, and extends beyond, the relationship component of family capital, functioning as a "bridge" to resources that would otherwise be inaccessible or unavailable. The family network is the natural organizational configuration within which a range of human, economic, social and other resources may be found and exchanged. The "flow of capital" in this context occurs in connection with the culturally defined obligations, duties, rights and expectations inherent in the various relationships. At a minimum, its "coin" is not material but is represented by the emotional, psychological and functional activities that are exchanged based on the particular relationships. Some of the considerations relevant to the relationship component include the presence and nature of multigenerational and same-generation relationships, and physical and emotional "presence" in the same household or nearby. Births, deaths, marriages and divorces affect the size and strength of the family network and therefore the amount and nature of family capital available.

As implied above, the family network represents the foundation of family capital. However, this network is not a single, uniform entity; its nature and scope vary from one setting to another and must be defined from a sociocultural perspective. The variables to be considered in such an exercise include the perceived, recognized and/or acknowledged extent of the bonds, responsibilities and obligations within the family network, the levels and forms of emotional and physical support, and the level of access to family resources and other internal "assets". At present there are no agreed family network indicators. At a minimum, the network is likely to include family members such as grandparents, parents, children, and the siblings of those in each generational category, whether resident or non-resident. In many cultures, however, families have relationships involving customary and sometimes legal obligations with additional members of the kinship or tribal group, and in these settings it is the larger grouping that represents the acknowledged family network.

In broad terms, the resource component of family capital reflects the net "value" of the material and financial assets, instruments (including those ensuring support or protection, such as life, health and property insurance, as well as tools, equipment and other material items), income, productive output, knowledge, skills and education that are found within the family network and may be drawn upon by its members. The relevant resources include the following:

- Income and remittances;

- Health, life, unemployment and property insurance;
- Housing and living space;
- Land, equipment, tools and goods;
- Food and food security;
- Knowledge and skills;
- The education of family members.

The resilience component of family capital comprises two elements: that which derives from the overall sociocultural context of the community or society; and that which derives from the unique qualities inherent or acquired within individual families. Sociocultural factors that affect the level of family resilience include the following:

- Human security;
- The social capital accessible to the family, including religious affiliation and practice and the presence of social and/or other moral points of reference;
- The availability of childcare and/or other forms of support for single mothers;
- School and community integration of individuals and families.

Those factors that appear to be attributable to the individual family include the following:

- The economic situation;
- The degree to which gender equity is given expression within the family through means such as spousal communication and joint decision-making; equity in the education of girls in the family; and shared decision-making in the allocation of household resources;
- Intrafamily communication skills;
- The level of domestic violence and/or substance abuse (if any);
- Parenting skills, including intrafamily contributions to the building and maintenance of individuals' self-esteem, the development of a positive self-image, and the promotion of autonomy;
- Intrafamily respect for the integrity of individual family members coupled with recognition of their interdependence;
- The sense of personal efficacy and resourcefulness among family members.

Intrafamily communication and gender equity represent family capital assets, whereas domestic violence, abuse and gender discrimination represent serious liabilities. Practices that are intended to strengthen family capital accumulation, such as the rituals surrounding birth and marriage, may in certain situations become critical liabilities if they significantly reduce the current or future well-being of the family by endangering the health of one or more members or by promoting indebtedness, the early marriage of girls or bonded labour.

Family capital is accumulated in both traditional and modern societies. It increases through marriage, with the birth of wanted children, and as family members are educated and acquire technical knowledge and skills. It is enhanced to the extent that the family environment is free of gender discrimination; to the degree to which family members support and facilitate the equitable development of all women and children within the family; and as the family interfaces with the rest of society. Demands are placed on family capital during natural and man-made disasters, armed conflict, and periods of illness or incapacitation, and as a consequence of deteriorating economic or environmental circumstances.

Most indicators of family capital can be measured and/or characterized; some, however, may be less definable or quantifiable. The scope of family capital first becomes apparent with the measurement of the family network. The extent to which the resources of family networks may be drawn upon is largely determined by regulatory, judicial and/or customary law, as well as by the quality of intrafamily relationships, levels of communication, and family and personal perceptions of familial obligations. Geographic proximity is an important variable affecting the formal and

informal bonds within family networks, influencing both the demands on and expenditure of family capital.

2.4 The vulnerability of families

The vulnerability of families can be thought of in terms of the absence or erosion of family capital. HIV/AIDS affects entire families, but some members, including women, children and older persons, are more vulnerable than others regardless of their serostatus. The social and economic vulnerability of certain groups, such as minorities, migrants, refugees, the landless and the unemployed, compound the intrinsic vulnerability of the family.

Within the context of the present analysis, the vulnerability of a family can be assessed at three levels:

- The family's ability to function in a variety of stressful and adverse settings and circumstances;
- The risk of a member of the family becoming infected with and transmitting HIV;
- The risk of relatively rapid progression of the disease in a family member and the death of that member, which accelerates the onset of an adverse impact on the family.

In terms of family function, vulnerable families can be described as those likely to experience the following:

- The inability to meet the basic needs of their members in the areas of health, nutrition, shelter, physical and emotional care, and the personal development of individuals;
- Physical or psychological exploitation, the abuse of individual members, discrimination against the family or individual members, injustice in the distribution of rights and responsibilities, and/or distortion of the roles of family members;
- A higher likelihood of breaking up as a consequence of external economic, social and/or political factors.

Many societies are changing so rapidly that the speed of change alone is a major factor of stress in families. Never before have there been so many and such dramatic changes in such a short time. Human beings are often unable to adapt to these changes as they occur; they need some time to learn and internalize new attitudes and behaviours. In many societies, long-standing traditions surrounding child-rearing or spousal relations, for example, have become outmoded before new conventions are developed or accepted, creating a kind of normative vacuum. The family has responded to these changes in ways ranging from adaptation without significant dysfunction to total breakdown.[39] Each of the three HIV/AIDS epidemics constitutes just such a challenge.

Topouzis and du Guerny emphasize that strategies for reducing vulnerability to HIV/AIDS must address the most basic needs of those at risk,[40] as indicated in box 2.

The ability to adapt or cope in difficult circumstances is described as resilience. It is the capacity of a person, group or community to prevent, minimize or overcome the damaging effects of adversity. Resilient behaviour may take the form of maintenance or normal development despite adversity, or it may promote growth beyond the present level of functioning. Resilience is typically thought of as a quality exhibited in response to adversity, but it may also be developed in anticipation of inevitable adversities.[41]

Large numbers of families can be considered vulnerable in a variety of circumstances created by forces beyond their immediate control—including war, drought, famine, racial and ethnic discrimination and violence, and economic deprivation. Labour migrants seeking to escape poverty, single-parent families, refugee and displaced families, and those whose livelihoods have been destroyed by environmental degradation are but a few examples of groups whose family resilience is severely tested. Families affected by HIV/AIDS now constitute the fastest-growing group of vulnerable families. The strength and structural integrity of families

affected by the disease are being further compromised—and their level of vulnerability therefore compounded—by other risks.

Certain characteristics of vulnerability put family members at risk of acquiring HIV, and others are thought likely to accelerate the course of the disease. It is well established that the risk of HIV infection increases in the presence of STDs, and that malnutrition[42] and concurrent infectious diseases, in particular tuberculosis and malaria, contribute to the more rapid progression of the disease. For women, age and the degree of physiological and psychosexual maturation are important, while for the mother-child dyad, pregnancy, delivery, breastfeeding[8] and malnutrition (especially vitamin A deficiency) are factors that may affect the course of the disease.

Vulnerability is also an important concept in examining AIDS and the family in the context of agricultural/rural development. Relevant considerations include the vulnerability of farming systems to drought, vulnerability to food insecurity, the vulnerability of farming families displaced from their land by conflict, and the vulnerability of returning refugees. Vulnerability to HIV adds an extra dimension to other vulnerabilities, with important implications for rural households.[40]

In general, unless the forces of change are too destructive to be resisted, families respond to crises with surprising resilience, and the essential functions of the family often survive the most intense assaults. For example, groups of street children often care for their younger members within a supportive family-type structure. Local communities spontaneously look after their older and sick members, supporting them emotionally as well as physically. Unfortunately, the HIV/AIDS epidemic in many settings appears to constitute such a destructive force that it overwhelms the resilience capacity of affected families and their communities.

Box 2. HIV vulnerability reduction strategies

HIV vulnerability reduction strategies refer to measures designed to address the underlying factors that create an overall climate in which ... risk-taking behaviours are encouraged, maintained and prove difficult to change. ... Addressing vulnerability to HIV entails the improvement of the socio-economic and living/working conditions and circumstances of rural men and women (and their children) so as to ensure that during periods of stress, household coping strategies and social safety net mechanisms are resilient enough to withstand the crisis. Therefore, HIV/AIDS vulnerability reduction strategies do not address the specific high-risk behaviour but the underlying factors that are responsible for this behaviour—taking into account the interrelationships between these factors and HIV/AIDS. This understanding of vulnerability reduction strategies is in tune with the mandate of agricultural and rural development programmes, as the factors underlying risk behaviour (poverty, food insecurity, migration, etc.) are integral concerns of such projects. For instance, vulnerability reduction strategies for construction workers and agricultural estate workers would include improving living conditions for workers living away from their families; making provisions for migrant and seasonal workers to regularly visit their families; facilitating and securing the sending of remittances, etc. Strategies to reduce the vulnerability to the impact of AIDS among subsistence farmers would include the promotion of low-risk, low-input and labour-extensive sustainable agricultural production systems.

Source: Excerpted from D. Topouzis and J. du Guerny, *Sustainable Agricultural/ Rural Development and Vulnerability to the AIDS Epidemic*, UNAIDS Best Practice Collection (Geneva, FAO and UNAIDS, December 1999), pp. 12 and 67.

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CHAPTER 3
FAMILIES AFFECTED BY HIV/AIDS: AN OVERVIEW

3.1 Methods, data sources and indicators for deriving estimates of families affected by HIV/AIDS

The current analysis is based largely on cross-sectional studies; a limited number of long-term studies that generally cover well-defined but circumscribed areas; two sets of national surveys using common definitions and methodologies (the DHS and MICS); and mathematical models used to describe the HIV/AIDS epidemic and to identify population characteristics, developed by UNAIDS and the United Nations Population Division respectively. Additional sources of information include sectoral impact studies sponsored by the Food and Agriculture Organization of the United Nations (FAO) and longitudinal studies from Tanzania and Uganda. The cross-sectional and long-term studies provide descriptive data and the results of knowledge, attitude and practice surveys. The DHS and MICS and many of the ad hoc reports address intrafamily and family capital issues.

3.1.1 Modelling

Epidemiological models have long been used for estimating the global magnitude and predicting the future impact of HIV/AIDS. They have been utilized for advocacy purposes, to forecast the impact of HIV/AIDS on mortality and population growth,[43] and to estimate the numbers of children orphaned as a result of the epidemic.[44, 45] They may also be useful in the development, planning and evaluation of national policy options and intervention strategies.

The models, developed by a UNAIDS/WHO expert group, provide estimates of national HIV prevalence and incidence rates. To obtain these estimates, sampling or sentinel surveillance systems are used for the collection of data on women attending selected antenatal clinics.[46, 47] In countries in which it is epidemiologically appropriate and in which relevant facts and figures are available, the models may also incorporate data from surveys of female sex workers, IDUs, men who have sex with men (MSM), and other high-risk groups. Results from the testing of blood donors and/or donated blood constitute another source of information. The DHS for Mali (2001), Zambia (designated 2001-2002 but covering a portion of each year), Kenya (2003) and Ghana (2003) have included a serological survey of a subsample of the DHS population sample (see annex II). The national population estimates are based on the most recent United Nations data.[21]

Among the factors and variables incorporated in the models are the following: an indicator of fertility, such as the total fertility rate; epidemiologically derived information on the probability of male-to-female, female-to-male, and mother-to-child transmission; the mean interval from HIV infection to the onset of AIDS or an AIDS-related illness;* and the mean interval between the onset of AIDS or an AIDS-related illness and death. Both the HIV-to-AIDS and AIDS-to-death intervals are influenced by the age of the individual at the time of HIV infection, the nutritional patterns and diseases prevalent in the community (with tuberculosis representing a particular concern), and access to health care and treatment.[48, 49]

The outcome results from the models are affected by the completeness and reliability of the available information, as well as by the choice of assumptions for the relevant rates in the models. These caveats are equally applicable in deriving the numbers and rates for estimates and projections relating to families affected by HIV/AIDS.

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* AIDS-related or AIDS-defining illnesses include tuberculosis, wasting syndrome, cryptosporidiosis, cyclosporiasis, candida esophagitis, toxoplasmosis, and cryptococcal meningitis (see annex I).

3.1.2 Deriving estimates of the total numbers of families

The number of family households is the best and currently the only practical measure for estimating the total number of families in a country or region. Although the DHS data sets and many national censuses contain data on the relationships of household members, the published data are usually presented in terms of the household. Two published sources of national household survey data—the DHS and MICS—have been used on an interim basis to obtain relevant estimates for the present publication. From the reports based on these surveys it has been possible to derive estimates of family households for 36 sub-Saharan African countries (see annex II). The methodology, definitions and presentation format used for the survey data are virtually identical. The operational definition of family households is all households with more than one occupant. A national census undertaken in 2000 indicated that 30 per cent of all households in the United States were non-family households; however, only one fifth of those (a total of 6.1 per cent) were composed of two or more people.[50] For virtually all developing countries the prevalence of multiple-person households of unrelated individuals is no greater than 1 to 2 per cent, which is sufficiently small as to be discounted in estimating the numbers of family households in developing countries.[25]

To derive the total number of households for each country, 2001 and 2003 estimates of the total rural and urban population[21] for the 36 sub-Saharan African countries have been divided by the mean number of persons per rural and urban household as estimated primarily from the DHS and subsequently from MICS sample data. The total number of family households has been obtained by subtracting the DHS and MICS percentages of one-person households from the total households in each country. Estimates have been derived separately for urban and rural areas; however, because the published UNAIDS indicators used in this analysis are not disaggregated by place of residence, the estimates of families affected by HIV/AIDS have been based on total family households.

3.1.3 Deriving estimates of families affected by HIV/AIDS

Four indicators are used to define and characterize the impact of the HIV/AIDS epidemics and identify appropriate responses to facilitate the development of family-focused policy and programme options. Three of these indicators, reflecting the progression of HIV/AIDS in the family, have distinct policy and programme implications. The fourth, representing the sum of the three, provides an overview of the current, and possibly the future, magnitude of the impact in a country. The indicators relating to the stages of HIV/AIDS are the numbers and percentages of the following: (a) families with an adult HIV-positive member in residence; (b) families that have a resident adult member with AIDS or an AIDS-related illness; and (c) families affected by the death of one or both parents from AIDS, as measured by the numbers of families with orphaned children. When estimated sequentially in reverse order (as noted below) and added together, they constitute the fourth indicator: families affected by HIV/AIDS. For the present analysis, the comprehensive UNAIDS report published in 2004 has served as the source of information and statistics on people living with HIV/AIDS, children orphaned by AIDS, AIDS deaths, and HIV prevalence.[6] The inclusion of data for 2001 and 2003 in the 2004 report has facilitated the development of an additional indicator, namely, the rate at which families are newly affected by HIV/AIDS, also referred to as the incidence rate of families affected by HIV/AIDS.*

* Incidence is the frequency with which an event occurs during a specified period of time. The incidence rate is the number of new events per specified unit of population. (see B. MacMahon and T.F. Pugh, *Epidemiology: Principles and Methods* (Boston, Little, Brown and Co., 1970) For the current analysis the incidence per 1,000 families is based on the annual difference in the number of HIV/AIDS affected families between 2001 and 2003, divided by the total number of family households minus HIV/AIDS affected in 2001.

The estimates of families affected by an adult AIDS death have been derived from the numbers of living children orphaned by AIDS, adjusting for the numbers of children in the affected households. From the DHS or MICS data the mean numbers of rural and urban orphans per family household have been combined and reduced by a factor of 0.2 to account for the lower fertility rate observed among HIV-positive women.[51, 52, 53] Child deaths have not been included in the characterization of families affected by an AIDS death despite the fact that the death of an infant or child frequently occurs before the death of the mother from AIDS. Virtually all such children have acquired their infections through MTCT, and a child's death has less of an impact on the family and family capital than does a parental death.

The indicators published by UNAIDS do not distinguish those living with AIDS or AIDS-related illnesses from asymptomatic individuals living with HIV. For the present analysis, estimates of the numbers of families affected by adult AIDS or AIDS-related illnesses have been derived from the numbers of adult deaths from AIDS in 2001 and 2003, which were obtained by first estimating the number of child deaths,* then subtracting that figure from the total number of adult and child AIDS deaths cited in the 2004 UNAIDS report. The estimation of the numbers of families affected by adult AIDS or AIDS-related illnesses has been based on the following assumptions derived from the medical literature: (a) the number of AIDS deaths in a given year is representative of the number of persons living with AIDS or AIDS-related illnesses the previous year; (b) the number of adult AIDS deaths has to be adjusted for the epidemiologically derived mean interval of time between AIDS symptom onset and death, as recorded for countries in sub-Saharan Africa; and (c) virtually all adults with AIDS or AIDS-related illnesses remain in or return to the family household once symptoms reach the point that supportive care is required. No adjustment has been made for unmarried family members in such circumstances, as these individuals are also likely to stay with or return to their families of origin or to live with other relatives. In either case, the families in which these afflicted members have been absorbed are factored into the estimation of families affected by adult AIDS or AIDS-related illnesses. AIDS deaths among HIV-positive individuals also serve as an indicator of the AIDS case mortality rate in a country.

The estimates of families affected only by adult HIV have been obtained by subtracting those families identified as being affected by adult AIDS or AIDS-related illnesses from the total numbers of families affected by adult HIV/AIDS, based on the UNAIDS indicator "adults living with HIV/AIDS". The results are also based on several assumptions. It is widely recognized that in most African countries more women than men are HIV-positive, and that infection tends to be disproportionately even higher among younger women, many of whom have yet to marry or enter into a common-law union. Therefore, estimates of maternal HIV infection were derived first by limiting the analysis to those women who, at the time of the survey, were or had ever been in a marriage or common-law union. The resulting numbers reflected situations of HIV seroconcordance, where both partners were infected, and serodiscordance in which only the woman was infected. To these numbers were added estimates for discordant couples in which only the resident male partner was infected. The few available serological studies on HIV concordance and discordance among cohabiting couples indicate positive male HIV discordance equivalent to between 35 and 45 per cent of concordant and discordant female HIV infection.[54, 55, 56] To err

* Child deaths were estimated by applying a calculated 40 per cent annual progression rate of pediatric HIV to death to the number of children living with HIV, based on the model taken from the United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 1998 Revision* (New York, 1999), as cited in United Nations, "AIDS, mortality and population change", a report from the Technical Meeting on the Demographic Impact of HIV/AIDS, organized by the Department of Economic and Social Affairs, Population Division, in collaboration with UNAIDS (New York, 10 November 1998).

on the conservative side in estimating a reasonable number of discordant HIV-positive male partners to add to the estimated number of concordant and discordant HIV-positive ever-married women, the latter was multiplied by 20 per cent instead of 40 per cent to arrive at the total number of families affected by adult HIV. This approach took into account the higher number of female-headed rural households (as a consequence of spousal death or husband/father absenteeism). The objective here has been to estimate the number of families, rather than the number of individuals, affected by adult HIV in each of the countries under review. The method that has been used up to this point takes into account the concordantly infected husband and wife, without a correction for the possibility that another adult in the same family household might be infected with HIV. Without an appropriate "reduction" factored in to account for such a possibility, there is a good chance the affected families will be overcounted. To adjust the estimates of families affected by adult HIV for the possibility of an additional HIV-positive resident adult in the household, the estimates of the numbers of affected families have been reduced by the adult prevalence rates squared.

The work undertaken within the present context has included not only the estimation of incidence and prevalence rates for families affected by HIV/AIDS, but also an examination of some of the correlates of the variations in these rates among the 36 sub-Saharan African countries under review. To the extent permitted by the available data, consideration has been given to such issues as women-headed households, the household living arrangements of children, and traditional practices. The Microsoft Excel© spreadsheet regression function has been used for the respective analyses.

3.1.4 Comments on the methodology

Neither the indicators nor the analysis presented in this publication can be considered definitive or final. First, the assessment has been based on published aggregated data rather than on the primary data files of the respective surveys, which contain far more information on family structure. The more recent DHS include an HIV serology module and are well suited to an examination of the relationship of HIV to family structure. Second, estimates of the total numbers of households may be greater than the "true" estimates, given that the DHS and MICS are based exclusively on a household sample survey design, whereas census results and national population estimates include individuals living in group quarters such as correctional institutions, nursing homes, school/university dormitories, and military quarters. Around 2.8 per cent of the United States population enumerated in the 2000 census were living in group quarters;[57] however, comparable populations in developing countries are likely to vary greatly. Some of these groups—including dormitory-housed migrant labour engaged in mining, manufacturing and commercial farming, as well as those living in military quarters[58, 59] and correctional institutions—are circumstantially more prone to HIV infection.

Tuberculosis requires special consideration in modelling the impact of HIV/AIDS on the family; it is an important component in examining AIDS-related illnesses and the family, and HIV plays a critical role in the clinical and epidemiological course of tuberculosis in any setting. Tuberculosis, like AIDS, is chronic and insidious. The household is a prime site for the transmission of the infecting organism, and AIDS has been shown to increase and prolong the communicability of tuberculosis. Furthermore, the tubercle bacillus—especially in the presence of HIV infection—is becoming increasingly resistant to the inexpensive first line of antimicrobial therapy.

It will be necessary to ensure technical agreement on the family-relevant indicators within the scientific community and among the concerned agencies and organizations of the United Nations system. As implied earlier, the development of appropriate and consistent definitions and methods for undertaking assessments relating to the subcategories of families affected by HIV/AIDS is essential, as the formulation of effective family policy must

be based on scientifically sound, locally relevant research and policy/programme evaluation.

3.1.5 The family network: estimation and characterization

In many developing countries the family network represents the primary, and often the only, source of care and support for those suffering from AIDS. In spite of this fact—but consistent with the "individual behaviour" emphasis of the traditional response to the epidemic—there appears to be little research specifically addressing the family network and AIDS in individual countries or cultures, and even less relating to how family networks in different settings have succeeded or failed in addressing the care and support needs of member families affected by HIV/AIDS. One problem is the absence of the operational definitions and comparable methodology required to measure, observe and assess the response of such networks to the epidemic.

There is a clear need to establish operational definitions that are conceptually adaptable to different settings. Indicators should undergo field testing and, once finalized, be appropriately included in survey components such as the DHS module on HIV/AIDS. Similar modules, thus adapted, would be equally relevant to other social policy priorities such as the care and support of older people and individuals with disabilities. One of the potentially important dangers the HIV/AIDS epidemic poses for the family and the family network is that the stigma and burden of the disease can erode the functional capacity of either or both institutions. It is essential to determine the extent to which this may be occurring so that targeted remedial measures and policies can be formulated. For both social policy and social welfare purposes, further research on family networks seems warranted.

3.1.6 Beyond models and the epidemiological categorization of families affected by HIV/AIDS

While models are useful for monitoring the HIV/AIDS epidemic and developing policy options and programme strategies, more information is needed to fully engage and protect the families confronted with the challenges attendant to HIV infection and its aftermath. Because of the specificity and differences in needs and the related policy and programme implications, it is useful to provide separate estimates for the subcategories of families affected by HIV/AIDS. Among the subgroups are those who are aware and those who are unaware of their HIV status. Only a small percentage of HIV-infected family members have been tested, fewer have been informed of the results, and even fewer have discussed their serostatus with other family members. Even when experiencing clear symptoms, family members may be unaware that they are suffering from HIV/AIDS, or may be aware of the situation but in a state of denial. Planning for the future is rare.

While family capital may be appealing as a conceptual framework for the translation of policies and strategies into targeted programmes, further methodological development and testing are needed to ensure its applicability. Intrafamily communication, the presence or absence of discriminatory attitudes, and patterns of economic migration are some of the major factors affecting the risks faced by families and their capacity to protect themselves and deal with the adverse effects of the epidemic.

3.2 An overview of the number and distribution of affected families

The impact of HIV/AIDS on the family and the family's response to the attendant challenges are a function of the following:

- The stage and duration of each of the three epidemics;
- The main social, behavioural and epidemiological characteristics of each of the three epidemics in the context of the particular economic and ecological circumstances of the community, region and country.

It is widely acknowledged that families are the first to experience the full impact of each of

the epidemics; however, the extent to which they are able to deflect or cope with the various forms of stress arising from the epidemics is less well defined and understood. When the AIDS epidemic was first identified there was some theoretical speculation about how families and communities might be affected,[60] but no detailed or definitive conclusions were reached. There are many assumptions and generalizations about families in different regions of the world that obscure the detailed dynamics of family structures and relationships and the nature of family capital within specific populations and communities. These particulars largely determine the kind of impact HIV/AIDS will have on a family, and recognizing their significance should curb any tendency to draw generalizable conclusions from even the best of long-term studies, which are usually geographically or ethnographically limited.

It is only in the past few years that a critical body of research relevant to AIDS and the family has emerged, with substantial input from parts of the developing world. Most of the published research has been from North America, Western Europe, a limited number of sub-Saharan African countries and Thailand. Fortunately, there is sufficient variation in the findings among developing country reports that the methodological error of drawing generalized conclusions from too narrow a research base can be avoided. Even more fortunate is the availability of a large number of similarly designed household surveys (the DHS and MICS), particularly in sub-Saharan Africa, and the HIV/AIDS estimates for 2001 and 2003 published recently by UNAIDS using the same data sources and modelling procedures.[46] These materials have made it possible to carry out standardized country analyses and comparisons of trends over the past few years in 34 African countries.

Unfortunately, there is such a paucity of comparable research from the diverse cultures of Asia, Eastern Europe, the republics of the former Soviet Union, and Latin America and the Caribbean that the conclusions from existing research can only be put forward in hypothetical terms in these settings. Such research gaps represent a major impediment to scientifically sound policy and programme development.

Overview of the impact of HIV/AIDS on families in sub-Saharan Africa

A significant number of sub-Saharan African countries have endured extended periods of social and economic upheaval and often armed conflict, and in such circumstances the rate of HIV transmission accelerates, affecting an ever-increasing number of families. Depending on the nature of population movement and migration, the impact may be universal or predominantly urban or rural. In Uganda in the mid-1990s, "the socio-economic and political chaos in the country created an ideal situation for HIV to spread widely in both rural and urban areas".[61] Historically, in Uganda and many other countries, the family and "extended family system . . . has enabled the society to weather the many stresses of war and social dislocation which have occurred in the country for over two decades. It is anticipated, however, that the increased stress occasioned by AIDS will be too much for the extended family systems to bear in the long run."[61]

There are no global estimates of the numbers of families at the household level or of the numbers of families affected by HIV/AIDS. Estimates derived by the present author from published statistics indicate that in 2003 there were approximately 108.4 million family households in the 34 sub-Saharan African countries for which relevant national data were available, representing a 1 per cent increase in the number of families since 2001. Approximately 12.1 per cent of those households, or more than 13 million families, were affected by HIV/AIDS in 2003. This overall figure masks wide country-level variations in the numbers and relative proportions of families affected by adult HIV, AIDS, or AIDS death (see figures I and II and annex III, table 1) and the vast differences in the annual rates at which families were newly affected by AIDS between 2001 and 2003 (see table 1).

For assessments of family capital and coping capacities, and for the development of social

policies and programmes in support of families, it is important to distinguish between the three groups of families affected by HIV/AIDS and to identify the numbers and relative proportions of families in each category (see figure II). A family that includes a member living with HIV is in a position to conserve and even accumulate additional family capital if the infected member has been tested, identified and counselled, and has been able to devise a suitable plan for protecting and providing for other family members. An adult experiencing symptoms of AIDS or an AIDS-related illness must not only plan for the future of other family members, but must also secure the appropriate antiretroviral therapy and other forms of health-care support in order to prolong his or her capacity to maintain and increase family capital. Families affected by the death of a parent from AIDS face an entirely different set of challenges and must deal not only with issues relating to the restructuring of the family and the role of the family network, but also with concerns such as inheritance and property rights, traditional obligations including funeral costs and procedures, and the practice of levirate. Statistics for 2003 reveal that among the 13 million families affected by HIV/AIDS in the 34 sub-Saharan African countries for which relevant national data were available, one in eight were caring for an adult family member with AIDS, and more than one third had been affected by the death of one or both parents. Of all the families (those affected and those unaffected by the disease) in the countries under review, one in sixty were caring for an adult dying from AIDS, and nearly one in twenty included children orphaned by AIDS.

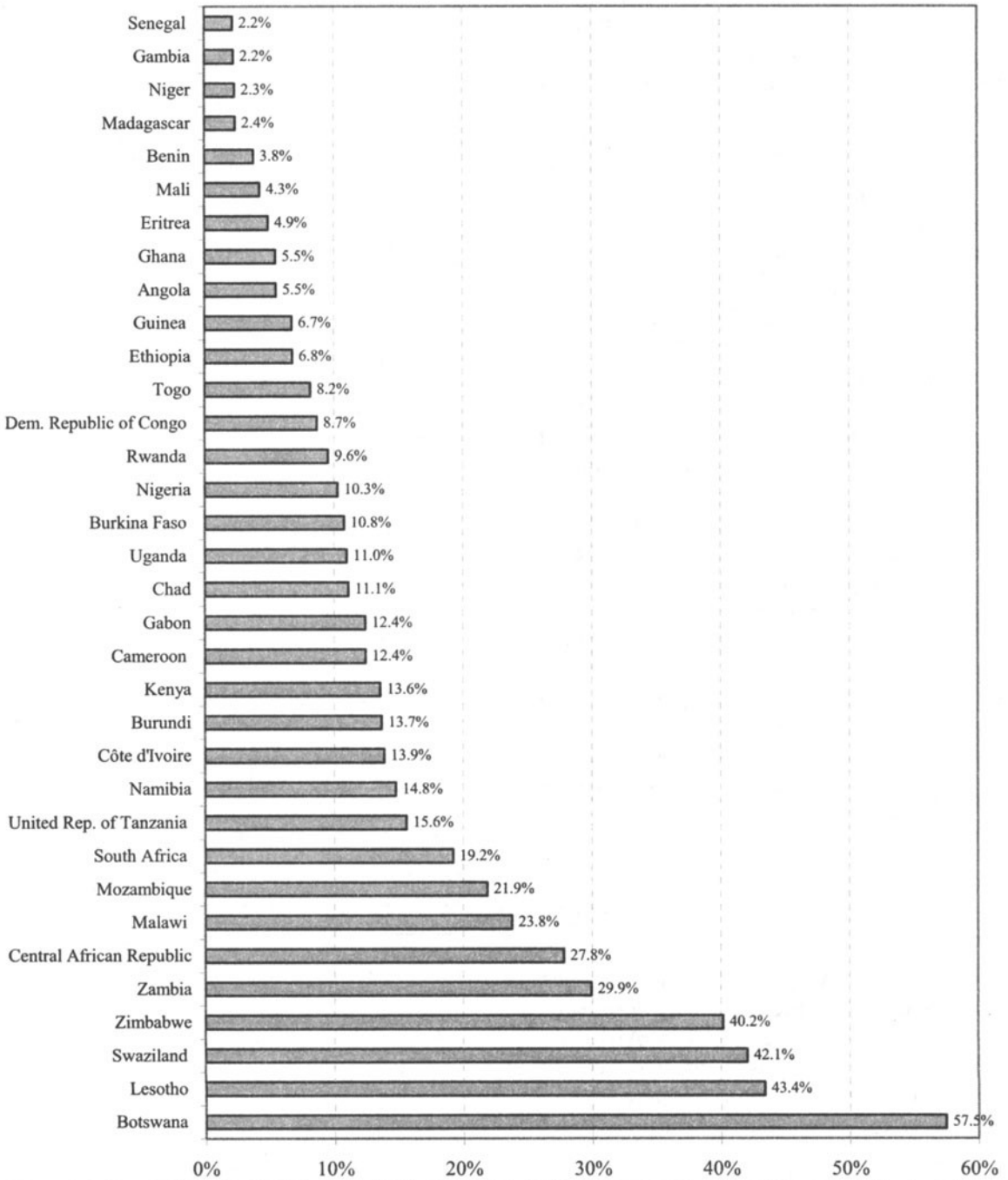
The variations and patterns characterizing country groupings and the previously designated groups of families affected by HIV/AIDS are exemplified in a comparison of two sets of countries with relatively high and low overall prevalence rates for 2003. In Burkina Faso, Chad, Nigeria and Uganda between 10 and 11 per cent of all families were affected by HIV/AIDS, while in Lesotho, Swaziland and Zimbabwe the corresponding rates were between 40 and 43 per cent (see figure I). Families that had experienced an adult AIDS

Table 1. Families newly affected by HIV/AIDS: average annual incidence rates for 34 sub-Saharan African countries, 2001-2003

Country	Annual incidence rate of families newly affected by HIV/AIDS/ 1,000 unaffected families	Annual incidence of families affected by HIV/AIDS
Botswana	32.0	4,100
Lesotho	31.9	6,400
Zimbabwe	26.2	38,600
Namibia	20.0	5 800
Swaziland	19.9	1,500
South Africa	19.8	141,800
Malawi	14.5	27,700
Gabon	13.8	2,100
Mozambique	13.3	37,900
Zambia	13.0	17,500
Burundi	9.2	9,800
Côte d'Ivoire	8.9	17,000
United Rep of Tanzania	7.2	39,300
Central African Republic	6.9	2,900
Guinea	6.9	7 700
Cameroon	6.5	14,600
Nigeria	6.2	118,100
Ethiopia	5.6	71 700
Angola	4.8	11,700
Chad	4.4	4,700
Burkina Faso	4.2	7,000
Togo	4.0	2,700
Madagascar	3.5	11,300
Dem. Republic of Congo	3.4	25,200
Kenya	3.2	15,4000
Eritrea	2.6	2,100
Rwanda	2.6	3,800
Ghana	2.5	8,400
Mali	2.5	5,200
Niger	2.5	4,700
Benin	1.6	1,700
Senegal	1.3	1,400
Gambia	0.6	100
Uganda	-3.4	-13 700

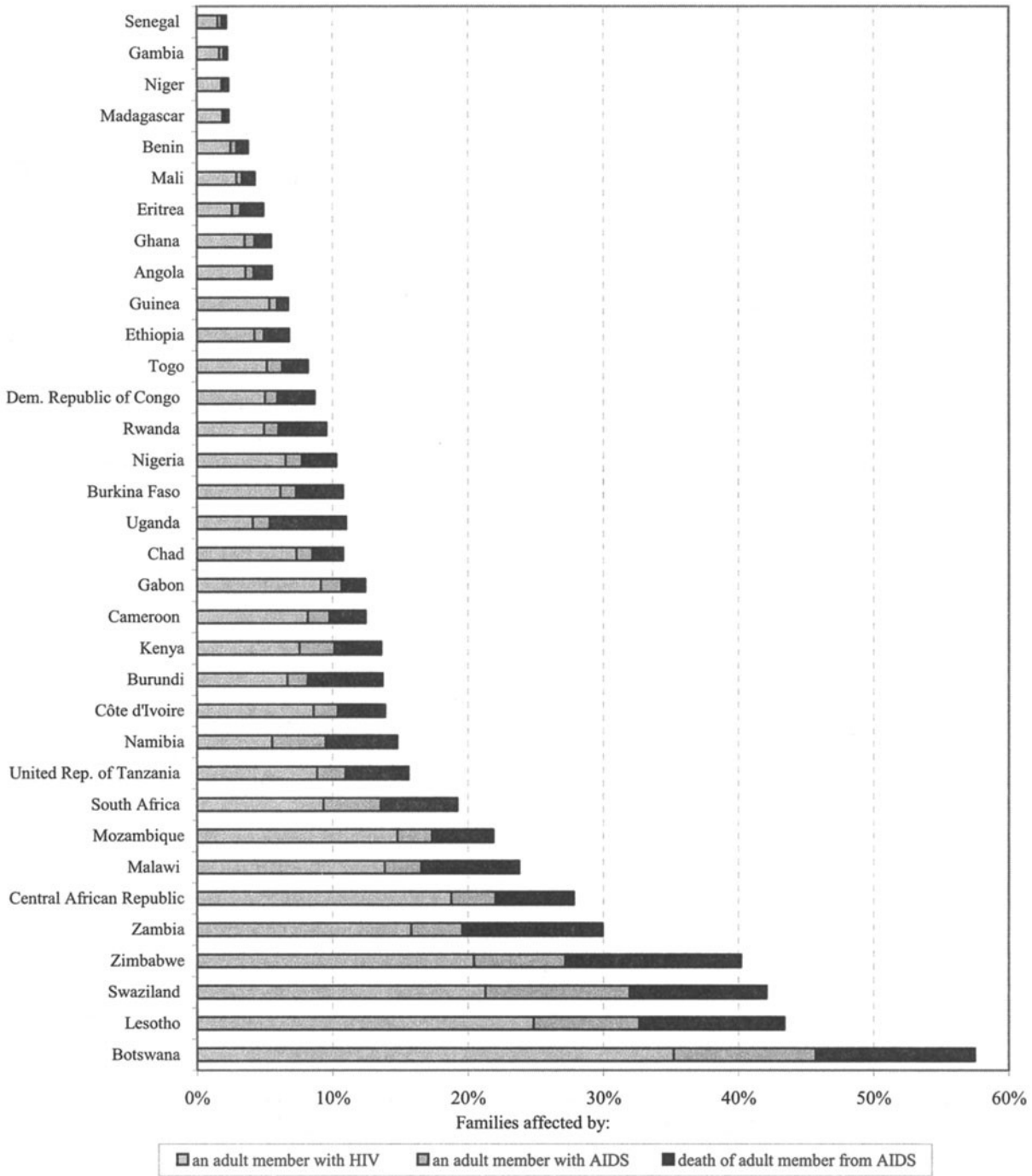
Sources: Data for the models and analysis were obtained from the 34 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2002 Revision* (CD-ROM) (New York, 2003) (United Nations publication Sales No. E.03.XIII.8).

Figure I. Percentages of families affected by HIV/AIDS in 34 sub-Saharan African countries, 2003



Sources: Data for the models and analysis were obtained from the 34 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2002 Revision* (CD-ROM) (New York, 2003) (United Nations publication Sales No. E.03.XIII.8).

Figure II. Percentages of families affected by adult HIV infection or AIDS-related illness or death in 34 sub-Saharan African countries, 2003



Sources: Data for the models and analysis were obtained from the 34 national Demographic and Health Surveys and UNICEF- sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2002 Revision* (CD-ROM) (New York, 2003) (United Nations publication Sales No. E.03.XIII.8).

death accounted for 51 per cent of all families affected in Uganda, whereas in Burkina Faso, Chad and Nigeria the same was true for only 32, 21 and 25 per cent of the affected families respectively. In Zimbabwe more than 32 per cent of the families affected by HIV/AIDS had endured the death of a parent, while in Lesotho and Swaziland only a fourth of those affected fit this description (see figure II and annex III, table 1). These dissimilarities are largely a reflection of the differences in the "maturity" of the epidemic in each of the respective countries. The rate for Uganda, however, also reflects the positive impact of the country's multifaceted programme to reduce the incidence of the disease (new cases of HIV infection in general).[62] Uganda is the only country to show a decrease in the proportion of affected families from 12.4 in 2001 to 11 per cent in 2003. It was the first country in sub-Saharan Africa to openly acknowledge a serious AIDS problem nearly 20 years ago, and from a global perspective has been among those countries showing the greatest political leadership and programmatic innovation in addressing the epidemic.

The family-HIV/AIDS model represents a potentially useful tool in the development and evaluation of family-relevant policies and programmes in different sectors. Because it is set up to highlight the epidemiological differences between countries, the model may also prove valuable as a means of directing and evaluating additional policy initiatives and can serve as a guide for countries in which the three epidemics are at an earlier stage. By distinguishing between the structures of families affected by HIV/AIDS and the particular stages they have reached, and subsequently deriving the relevant numbers and proportional distributions and monitoring the changes in these figures over time, it is possible to project immediate and long-term needs and to better evaluate the efficacy of a broad spectrum of sectoral interventions and support. This type of analysis indicates that at the aggregate level, the policies and activities implemented in Uganda have apparently produced a number of positive developments: between 2001 and the end of 2003 the absolute number of families caring for an adult member with AIDS declined by nearly 14,000, and the number of families with an HIV-infected adult member dropped by 20,000. Since the number of families in which children were orphaned owing to the death of a parent from AIDS increased by only 7,000 (see annex III, table 1), it is a reasonable assertion that the progression through the various stages (from infection to disease and death) has slowed. The data showed no decline in the total number of HIV/AIDS-affected families in any of the other 33 countries included in the analysis, though a few countries registered a decrease in the numbers of those affected by either HIV or AIDS. None of the countries recorded a drop in the numbers of families affected by an AIDS death.

The most recent UNAIDS sources, in which data for 2001 and 2003 were obtained using the same modelling methods, provide reasonable estimates of the rates at which families were newly affected by HIV/AIDS in the countries for which suitable data on family structure were available. Table 1 shows the annual incidence (numbers) and incidence rates (per 1,000 unaffected families) of families affected by HIV/AIDS in the countries under review. Between the end of 2001 and the end of 2003, more than 1.3 million additional families were affected by HIV/AIDS in the sub-Saharan countries included in the analysis; only Uganda registered a net decline, with around 28,000 fewer families affected. Nine of the ten countries in which the numbers of new families affected by HIV/AIDS grew by more than 10 per thousand annually were in southern or south eastern Africa, whereas the eight countries in which the numbers increased by less than 4 per thousand annually were scattered across north eastern, central and western Africa (see table 1).

Clearly, the epidemiological pattern of HIV/AIDS affecting families differs as widely in sub-Saharan Africa as it does elsewhere. Behavioural, traditional, economic, political and social factors all contribute in varying degrees to the widespread differences in the rising incidence and prevalence of families affected by HIV/AIDS. These factors will be explored in some depth in the chapters to come.

CHAPTER 4
KNOWLEDGE AND DISCLOSURE OF HIV STATUS

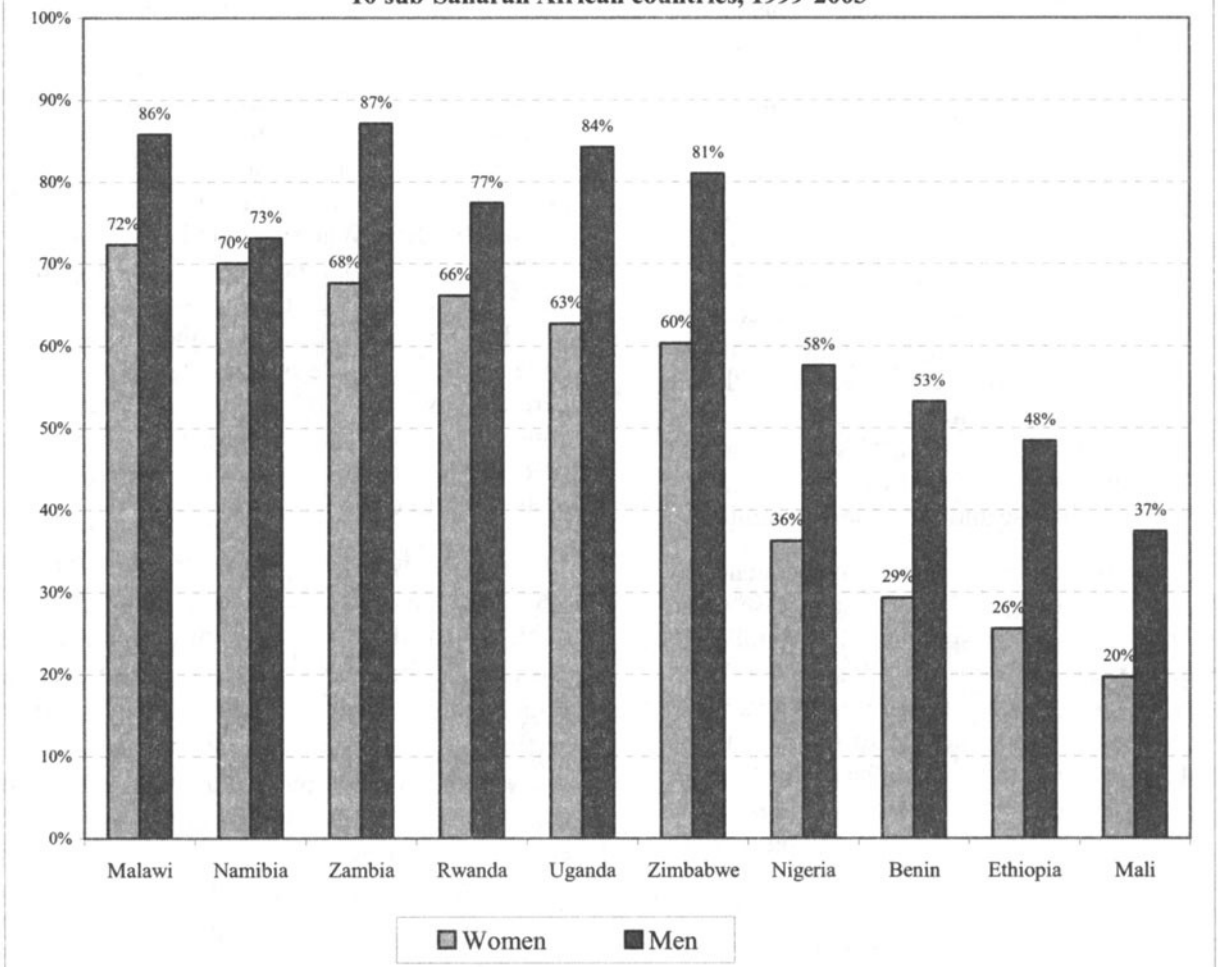
"Societies need to have one illness which becomes identified with evil, and attaches blame to its 'victims', but it is hard to be obsessed with more than one."[63] Illness metaphors can be positive or negative, can change over time, can apply to a single organ or the whole body, can be formed without regard to the biological facts, and can affect the whole life of the person carrying the diagnosis.[64] AIDS may be perceived as a plague, punishment from God or bad luck, depending on the social and cultural context. The fear, ignorance and misconceptions surrounding HIV/AIDS can interfere with the sharing of vital information that may allow individuals, families, communities and countries to better understand and address the causes and effects of the disease and the wider epidemic.

The basic process-and-outcome sequence of acquiring knowledge of HIV status, disclosing that knowledge, and responding as a family and community is the same in all settings. What distinguishes certain situations from others is the frequency and importance of different patterns and the changes and variations over time in different social and cultural settings. The coverage and adequacy of the testing system determine the start of the process, while the intrafamily culture and relationship patterns determine the outcome. Particularly important are the patterns of communication between conjugal and consensual partners. The more recent DHS have incorporated a component reflecting the perceived level of communication on HIV prevention between partners in stable unions, from the perspectives of both the men and the women. In seven of the ten countries in which married men and women were questioned, the proportions of men reporting discussions with their partners on the prevention of HIV were consistently around 20 per cent higher than the corresponding rates for women (see figure III). While the relatively high rate of reporting such discussions in some countries is encouraging, the discrepancy in perceptions between men and women is a matter of some concern in the context of intrafamily communication—particularly in rural areas, where the gap tends to be wider and the rates much lower.

Differences in the timing and circumstances of HIV testing for men and women have important implications for the integrity and functioning of the family, with women generally—and unjustifiably—bearing the greater burden. When a couple is apparently healthy, and if the country has relied on a sentinel system linked to antenatal-care services for deriving HIV estimates, the woman may have a greater chance of being tested. The male partner may be more likely to be tested in the course of seeking medical assistance for an STD or other illness, or as part of an employment-related health examination.

As the HIV epidemic extends beyond such high-risk groups as long-distance truck drivers, military recruits and female sex workers to include segments of the general population, it spreads from urban to rural settings; especially vulnerable are settlements, farms and villages along major trucking routes and communities that are sources of internal or international migrant labour. The urban-rural differences in HIV testing are significant. In most of the 26 sub-Saharan African countries with data on HIV testing among women, testing levels are much lower in rural areas, generally ranging from one fifth to one half of the corresponding levels in urban settings, and this is true whether national HIV prevalence is high or low. In a few countries with high HIV prevalence rates, testing levels in rural areas are only 25 to 30 per cent lower than in urban areas. In much of western and central Africa no more than 15 per cent of urban women undergo HIV testing, and, with the exception of Namibia, the corresponding rates for women in eastern and southern Africa are generally between 15 and 25 per cent (see figure IV). Testing

Figure III. Percentages of married women and men who have discussed HIV prevention with their spouses in 10 sub-Saharan African countries, 1999-2003

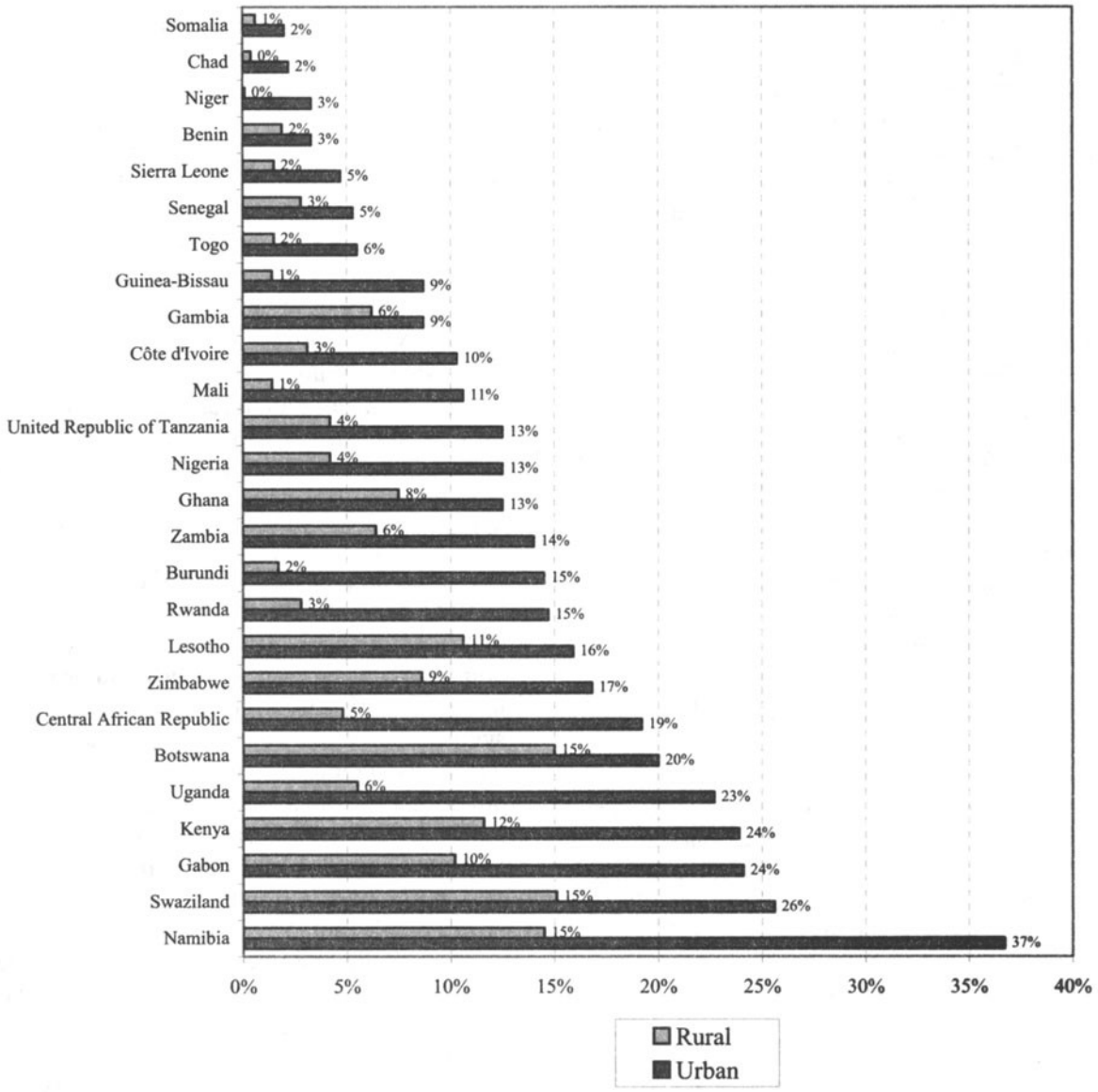


Source: Demographic and Health Surveys for Benin (2001), Ethiopia (2000), Malawi (2000), Mali (2001), Namibia (2000), Nigeria (2003), Rwanda (2000), Uganda (2000/01), Zambia (2001/02), and, Zimbabwe (1999).

rates for rural women range from 10 to 15 per cent in only six of the countries and are lower elsewhere. In 10 of the 12 countries* for which relevant DHS data are available, men are more frequently tested than women in the rural areas. In urban settings the differences are much less pronounced. Among men and women who have not been tested, 15 to 30 per cent express a desire not to be tested. Among couples that have formed a stable union (legal or common-law marriage), the diagnosis of a woman's HIV infection before the seropositivity of her asymptomatic male partner is confirmed has important implications for the process of disclosure within the family and for the family's response. Unfortunately, in such circumstances it is unlikely that either the husband or the family as a whole recognizes that the male

* Benin, Gabon, Ghana, Kenya, Mali, Namibia, Nigeria, Rwanda, Uganda, the United Republic of Tanzania, Zambia and Zimbabwe.

Figure IV. Percentages of women tested for HIV in urban and rural areas, 26 sub-Saharan African countries, 1998-2003



Sources: The 26 national Demographic and Health Surveys or UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003.

partner is the most likely source of the woman's HIV infection. The overwhelming majority of women in such unions are monogamous, while a significantly large minority of the men are not (see figure V). In nine of the eleven countries shown in figure V, at least 90 (and more often over 95) per cent of the women have been monogamous in the past year. The comparable rates of monogamy among men are far more variable.

The discovery of a person's HIV seropositivity or a diagnosis of AIDS generally has a disruptive effect on the entire family. While the expression of such an effect may vary, it occurs in all cultures. "The extent and duration of family disruption are influenced by history and strength of family bonds, previous experiences with illness and loss, and attitudes about HIV and AIDS."[18] The family's response is shaped by which family member is infected, the potential impact of stigmatization in the culture and community, and feelings of shame. As the family is forced to address the more practical long-term implications of the disease, its response may be influenced by the stage of HIV/AIDS at the time the family becomes aware of the situation, the level of care and diversion of resources required for the infected member, and the effect HIV/AIDS has on family capital and the family's position in the local community.

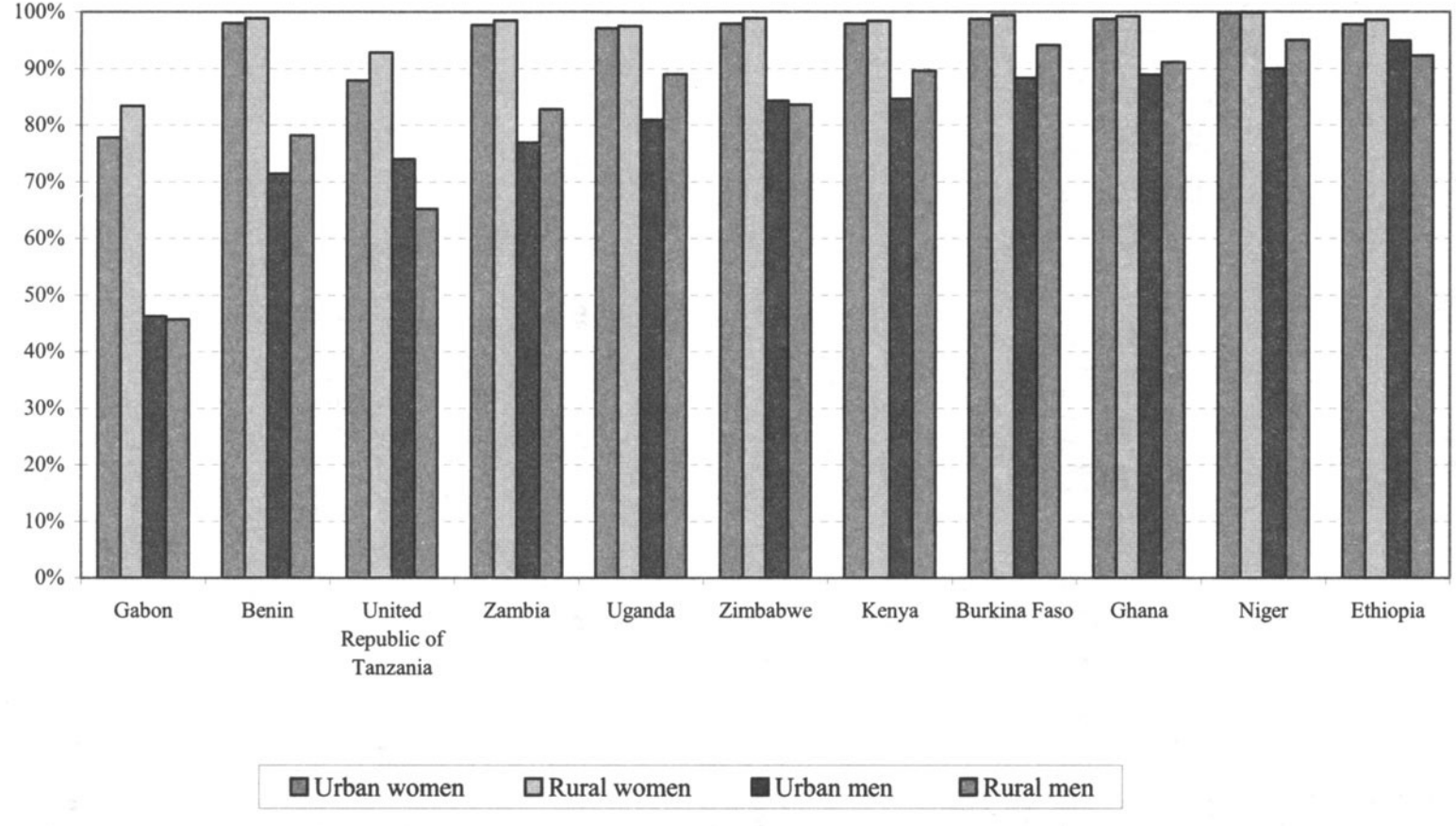
Family members may or may not be told that one or more of their number are HIV-positive. Those who are informed frequently express shock, disbelief and a fear of loss upon hearing the diagnosis but do not reject the subject or fear infection, contrary to the infected individual's expectations. More often than not, people with HIV/AIDS and their families fear rejection by those outside the household owing to the perceived stigma associated with the disease. In any case, "the labelling of someone as having AIDS relates to their physical condition, so with declining health, subjects and their families may avoid outside contacts. A direct impact of AIDS is to diminish mobility, decreasing available economic resources."[65]

4.3 Knowledge of HIV status

Knowledge of HIV status is critical to appropriate planning for the future. However, in most of the developing world, and certainly in much of Africa, neither the family nor the infected member is aware of the latter's HIV seropositivity in 85 to 90 per cent of affected families. Even when individuals are tested they may not be informed of the results. Among the 20 sub-Saharan African countries for which data are available, in only three have more than 10 per cent of the adult women been tested and informed of their HIV status (see figure VI). While countries with the highest estimated HIV prevalence tend to have higher rates of testing, these rates remain below levels that would permit family-focused voluntary counselling and testing (VCT). Health services that have introduced HIV counselling in their antenatal clinics generally lack the capacity to meet the demand for HIV testing. In Ghana, for example, 43 per cent of pregnant women attending such clinics received HIV counselling, but only 3.3 per cent were counselled, tested and informed of the test results.[66] Research on a subsample of the Ghana study group indicated that, when offered HIV testing, only 5.7 per cent of women and 10.7 per cent of men refused.[66] Refusal to be tested for HIV was higher among all groups in Kenya, Mali and Zambia, the three countries with studies similar to those conducted in Ghana, with rates of refusal appearing to bear little relationship to the HIV prevalence rate among those tested (see table 2). The points introduced here are examined in greater detail below.

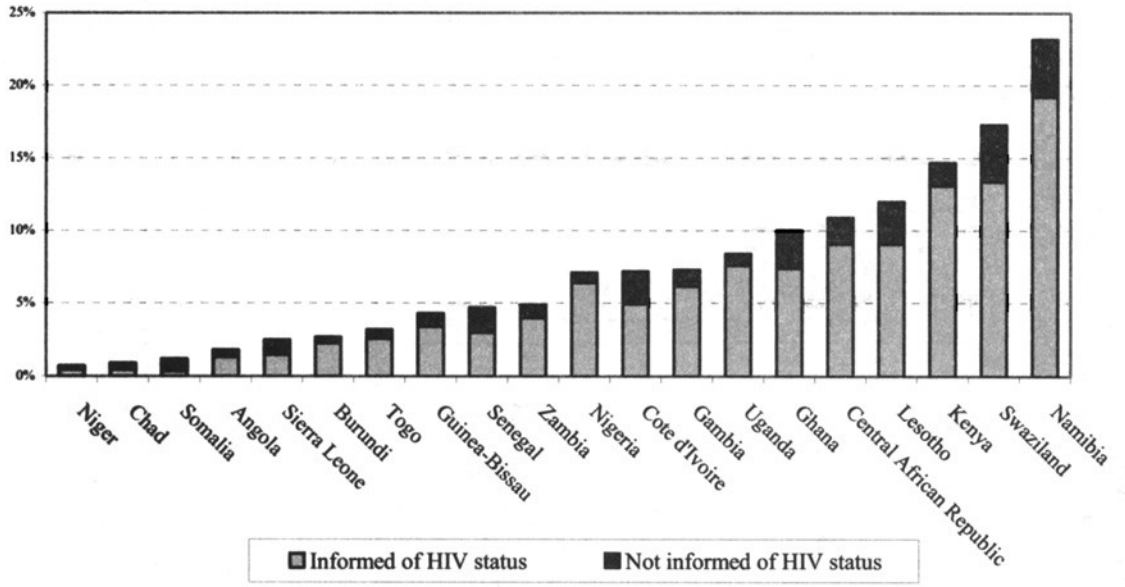
A family may not be aware of or affected by HIV/AIDS until such time as the disease interferes with the infected member's social obligations, economic activities and/or capacity for self-care and support. The "classic" symptoms of AIDS appear to be uncommon in many developing countries with a high prevalence of other infectious illnesses such as tuberculosis, malaria and diarrhoeal diseases.[10] In these settings, particularly in the absence of systematic VCT and with the lack of accessible or affordable therapy, the interval from the onset of the chronic, care-demanding illness to death is often too short for the family to develop coping strategies and plans for the future. Even in presumably the best of circumstances, systems for the serological testing of HIV status do not function optimally. In a large, multiple-country study of the experiences of HIV-positive patients in Europe, respondents "did not endorse the way HIV tests were conducted and positive test results revealed. Although there was an

Figure V. Percentages of women and men with no sexual partners outside of the marital or common-law union in the past year, 11 sub-Saharan African countries, 1998-2003



Sources: National Demographic and Health Surveys for Benin (2001), Burkina Faso (1998/99), Ethiopia (2000), Gabon (2000), Ghana (2003), Kenya (2003), Niger (1998); Uganda (2000-01); United Republic of Tanzania (1999), Zambia (2001/02), and Zimbabwe (1999).

Figure VI. Percentages of women tested for and informed of their HIV status in 20 sub-Saharan African countries, 1998-2003



Sources: National Demographic and Health Surveys for Angola (2001), Burundi (2000), Central African Republic (2000), Chad (2000), Côte d'Ivoire (2001), Gambia (2000), Ghana (2003), Guinea-Bissau (2000), Kenya (2003), Lesotho (2000), Namibia (2000), Niger (1998), Nigeria (2003), Senegal (2000), Sierra Leone (2000), Somalia (1999), Swaziland (2000), Togo (2000), Uganda (2000-01) and Zambia (2001/02).

Table 2. Percentage of men and women who were offered an HIV test but refused and HIV prevalence among those tested in Ghana, Kenya, Mali and Zambia, 2001-2003

(Percentage)

		Ghana	Kenya	Mali	Zambia
Women offered HIV testing but refused	Urban	6.8	19.2	19.9	15.6
	Rural	4.9	11.9	12.8	15.7
Men offered HIV testing but refused	Urban	15.1	16.5	32.9	16.2
	Rural	7.9	11.2	20.9	14.3
HIV prevalence among those tested	Women	2.7	8.7	2.0	17.8
	Men	1.5	4.6	1.3	12.9

Sources: National Demographic and Health Surveys for Ghana (2003), Kenya (2003), Mali (2001) and Zambia (2001-2002), available at http://www.measuredhs.com

improvement over time in the way HIV tests were conducted, they often did not conform to international guidelines."[67] Close to 14 per cent of the study consent, 15 per cent had been informed of their status by telephone or letter, and more than 50 per cent felt they had not been provided with adequate support when they were informed.

A pregnant woman's knowledge of her seropositivity is essential for the survival of her child(ren) and for prolonging her own health and survival. Relatively low-cost, easily administered treatment can markedly reduce

MTCT. If safe, affordable alternatives to breastfeeding can be provided or truly exclusive breastfeeding ensured, the risk of transmitting the infection through breast milk can be further reduced. The results of preliminary studies, though as yet unconfirmed, suggest that avoiding breastfeeding may prolong the survival of the mother, whose death would otherwise increase the risk of ill health or death in other, often uninfected children in the family.[8]

Rejection of VCT is neither uncommon nor fully understood. It may be partly attributable to a lack of understanding of or trust in the confidentiality of the process; to the fear of disclosure to family members or others; or to reasons associated with factors such as age, gender and education. Even when voluntary counselling and HIV testing are accessible, without cost, and offered in an environment of high community awareness, many adults do not take advantage of the services available. In large community-based studies in Tanzania and Uganda, one fourth to one third of the adults surveyed refused the offer of free and confidential VCT.[68, 69] In the Uganda study significantly fewer women than men chose to be tested.[69] In a separate Ugandan study among the female partners of male AIDS patients, only 12 per cent reported having any knowledge of their partner's AIDS diagnosis. While more than half acknowledged the need for HIV testing, only 5 per cent had been tested. [70] However, about half of the women reported that they had made plans for future support if their partners did not recover. In a study of women attending two STD clinics in the United States, 28 per cent declined HIV testing; neither a history nor the fear of partner violence was among the factors affecting the decision to be tested.[71]

4.2 Disclosure and the response of family members

There have been no collaborative multiple-country comparative studies published on the patterns of disclosure of HIV seropositivity to partners, family members or others. Research on the disclosure of HIV/AIDS status has largely focused on issues of partner notification, risk reduction and ethics. The subject has also been examined in the context of domestic and partner violence. Only recently has research addressed disclosure in the family context, primarily in connection with children orphaned by AIDS. Ideally, the well-being not only of surviving children but of all affected family members should be considered in multiple contexts, including the community, the family economy, and family capital. Disclosure, as it relates to family capital, assumes even greater importance as HIV testing and the means of preventing MTCT become increasingly accessible, affordable and acceptable, and as the combined antiretroviral therapy regimens are incorporated into specific policies and programmes in resource-poor communities and countries.

As important as research on disclosure has been, much of it has been relatively limited, presenting a "snapshot in time" rather than a dynamic picture of the circumstances surrounding disclosure and the subsequent adaptation and accommodation that normally occur in family responses to stressful or traumatic situations. A broader and more comprehensive research approach would provide a clearer idea of how families handle such challenges, and this information could be used to identify or devise appropriate support mechanisms and guide policy decisions. More in-depth coverage and analysis would reveal, for example, that even in industrialized countries the important process of informing children is best accomplished over a period of time.

Individuals who know they are infected with HIV must decide when or whether to tell their families or specific family members. Disclosure is an emotionally difficult task. It creates opportunities for both rejection and support. In some communities there may be self-imposed barriers to disclosure that are rooted in cultural values. Among Asian families in the United States, for example, barriers that might affect disclosure to family members include the protection of the family from shame and from the obligation to provide assistance, as well as the avoidance of communication regarding highly personal information. Some Asian Americans living with HIV/AIDS have indicated

that the lack of HIV education among relatives overseas may have inhibited disclosure.[72] Part of the difficulty may arise from feelings of shame, as knowledge of HIV status invariably leads to revelations regarding behaviours or practices previously unknown or denied and not discussed within the family.[73]

Disclosure may constitute both a stressor and a mechanism through which individuals contend with their infection and ultimately enhance their coping capacity and emotional and physical health.[74] Disclosure of HIV status is not merely a prelude to seeking psychological and emotional support from family members or friends. It must be considered primarily in terms of its broader implications, essentially deriving from the fact that it represents a literal moment of truth with potentially serious and long-range consequences. Stress is a defining factor regardless of whether the infected individual decides not to disclose his status or to move ahead with the disclosure and risk rejection, stigmatization and discrimination. Disclosure of a child's HIV diagnosis is a controversial and emotionally laden issue. The stigma of AIDS and its negative impact on the child and other members of the family constitute one important reason families avoid disclosure.[75] Such reticence, while understandable, may not represent the most effective response. The emotional conflict and stress experienced by someone who has HIV/AIDS but does not discuss the matter may directly affect the course of the disease, as measured by the body's immunological response. In a study conducted in the United States, children who had disclosed their HIV seropositivity to friends showed significantly greater improvement in laboratory measurements of disease severity than did children who had not yet shared their diagnosis with friends.[76]

A significant number of people with HIV/AIDS accept VCT but do not disclose their serostatus to anyone. In studies of AIDS patients and their relatives in Ghana[22] and Uganda,[65] one fourth to one third of the patients reported that they had kept the news of their diagnosis to themselves. The most frequent reasons given for not sharing such information included the fear of rejection or abandonment, the fear of being considered unfaithful, and the feeling that it was no one else's business or that others would not understand.

Anger, hurt, disbelief and denial are among the most common immediate reactions to the disclosure of HIV/AIDS in a family, followed in many cases by a sense of sadness and loss. The response of families is greatly affected by the quality of the relationships, judged on the basis of pre-existing patterns of support or discord, and by prevailing gender relations, with men generally receiving a less negative response than women. HIV/AIDS disclosure is met with a more positive reaction in situations in which the level of trust is high and spousal conflict is minimal than in contexts in which mistrust and spousal conflict prevail.[77]

Spousal or partner disclosure varies widely between countries and among subgroups; it is often infrequent and never universal. In Africa it has ranged from as low as 7 per cent to as high as 40 per cent.[22, 68, 78, 79, 80] The rate of disclosure appears to increase over time following diagnosis. In one study of pregnant women, an initial spousal disclosure rate of 22 per cent increased to 40 per cent after nearly four years.[79] The women were less likely to inform their partners if they were cohabiting, were employed in low-wage jobs, had previously disclosed their status to a female relative, or had ever used a modern method of contraception. Women who reported fewer than six lifetime sexual partners or knew someone with HIV/AIDS were more likely to disclose their status to their partners. In the Ghana study around 31 per cent of the respondents that had divulged the news of their diagnosis reported that their partners had reacted with outrage or indifference, and 6 per cent were unable to interpret their spouses' reactions; only 31 per cent could say with certainty that their spouses had been sympathetic.[22] Elsewhere in West Africa partner indifference was the most frequently noted response to a woman's disclosure of HIV seropositivity, with partner support evidenced in a minority of cases.[80] In another study only one sixth of the 288 women enrolled had disclosed their positive HIV status

to their sexual partners. Fears of stigma and divorce were cited as the main reasons for avoiding disclosure. Around 60 per cent of the informed sexual partners agreed to be tested for HIV.[68]

A number of studies suggest that there is a disjunction between how individuals believe their families will respond to disclosure and the actual responses of the families. In one study in an urban centre in Africa, family members did not express fear or rejection of the patients but instead tended to focus on the implications of AIDS, including the potential loss of a loved one, the burden of caring for the patient and perhaps the children left behind after the patient's death, and the forced modification of future plans.[65]

HIV-discordant couples* must address four major sets of issues: (a) the emotional and sexual impact of the disease on the relationship; (b) reproductive decisions; (c) plans for the future of any children and the surviving partner; and (d) disclosure of the HIV infection to friends and family. Findings regarding the handling of these issues have implications for the design of interventions to enhance the adaptive capacity of discordant couples.[81] In both industrialized and developing countries women bear the greater burden in serodiscordant relationships. In a study from the United States, positive serostatus was associated with increased support from health professionals, being neglected or disowned by the family, and the break-up of marriages, which was three times more frequent if it was the woman who was HIV-positive.[82]

Spouses of HIV-infected individuals make decisions based on their perceptions of social norms and expectations about their own future and that of their children. In a small, in-depth study of HIV-discordant couples in Thailand, one third were separated or divorced, while the relationships of the others remained intact. The five factors influencing marital stability following HIV notification included the duration of relationship, economic constraints, the opinions of extended family members (especially parents), the existence of children from the marriage, and the fear of stigmatization by community members. Among women, the decision to stay or leave seemed to be made most often in deference to a parental request and did not necessarily reflect their own inclinations.[83]

Early in the epidemic it was assumed that couples in which one or both partners were HIV-positive would not want to produce children; it was believed that women who were seropositive would not wish to become pregnant, or if pregnant would not wish to carry the baby to term. Subsequent experience in both developed[84] and developing countries suggests that the inclination to forgo childbearing is more the exception than the rule. A counselling programme for HIV-discordant couples was developed, implemented and later evaluated in Kinshasa, Democratic Republic of the Congo; the programme included an equal number of male and female HIV-positive partners. The evaluation confirmed that divorce was rare, couples were able to minimize their risk of HIV transmission, and unprotected sex occurred only during the couples' perceived monthly fertile period. Among the 178 participating couples there were 24 children born, only one of whom was HIV-positive. Of the six HIV-positive women attempting to become pregnant, only one was successful,[54] which provides anecdotal confirmation of the decreased fertility associated with HIV infection among women. In Burkino Faso, the results of a prospective study involving 306 HIV-positive women who had been informed of the risks relating to their sexual and reproductive health indicated that only 18 per cent had informed their partners of their seropositivity, a mere 8 per cent had used condoms for each act of sexual intercourse to avoid HIV transmission, and 39 per cent had begun using hormonal contraception. Pregnancy rates remained comparable to those within the general population.[85]

A woman who knows she is infected with HIV will usually inform her mother, a sister or

* Serodiscordant couples are those in which one member is HIV-positive and the other is HIV-negative.

another female relative. A man who decides to disclose that he is HIV-positive will generally inform his mother, a brother or a close male friend. In a study from Ghana,[22] over one third of the HIV-positive adults had shared their diagnosis with their mothers, and another 21 per cent had confided in their siblings. While most mothers (74 per cent) were quite sympathetic, a significant minority (20 per cent) were outraged. Around half of the brothers and two thirds of the sisters showed sympathy, but nearly a fourth of the brothers and 6 per cent of the sisters responded with indifference. Even among fathers, who were less often informed and more often outraged and unsympathetic, there tended to be an increase in sympathy and support over time. Nonetheless, a small core group of parents remained rejecting and unsympathetic. In another study, disclosure to a female relative was more likely if the infected individual knew more than two people with HIV/AIDS, was in a position of complete economic dependence on a partner, enjoyed a high level of social support, and had previously attended a support group meeting.[79]

In a multi-centred study in the United States, HIV-positive adolescents were more likely to disclose their status to their mothers than to their fathers. With disclosure, perceived support from either parent was high. Factors associated with higher rates of disclosure to mothers included the passage of time following diagnosis and Hispanic ethnicity. Factors associated with increased disclosure to sexual partners were the partner's HIV seropositivity and his or her status as the "main" partner.[86]

In some settings the negative feelings generated by the disclosure of an HIV or AIDS diagnosis wane as the disease progresses. In the Ghana study, for example, the proportions of sympathetic spouses and mothers increased over time. The study's authors speculate that the "wasting nature of the disease could have a powerful influence on people's emotions just as the effects of wars and famine have. Also, the traditional belief in the link between the living and the spirits of the dead could compel some people to be sympathetic to critically ill relatives. People do not want to incur the wrath of a dying person, fearing that the spirit of the deceased would take revenge."[22]

Stigma, discrimination, secrecy, and disclosure are important issues that define the unique challenges facing parents with HIV/AIDS.[87] After careful consideration of all the potential ramifications, seropositive mothers must decide whether, when, and how to disclose their diagnosis to their children and must arrange for future care. "It is not surprising that in the face of ... powerfully felt discrimination many families choose to keep their HIV status a secret from their children. ... Questions about maintaining secrecy also must be balanced with a recognition that all parents limit disclosure of private affairs with their children, and that this varies with the cultural beliefs of families."[88]

Children are among the last to know, if they are told at all, that they and/or one or both of their parents are HIV-positive. The tendency towards secrecy, or non-disclosure, may be attributed to the following: the belief that lower-age children should not be told (older children are more likely to be informed); the perceived need to protect the children from the stress, insecurity and other emotional responses associated with the acquisition of such knowledge; and the inclination to protect the family from inadvertent disclosure to non-relatives. Disclosure also raises such complex issues as transmissibility, maternal guilt, and the possibility of more than one family member being infected. For an infected child born to an HIV-positive mother, disclosure may affect medication adherence, treatment compliance, sexual exploration, and the child's developing autonomy, and may lead to fears associated with premature death. Such concerns and threats to a child's well-being are not always understood or acknowledged; in one study, "two thirds of the parents reported they believed their children did not need to talk to someone about their parent's health, and nearly half of the parents reported that they did not need help dealing with their children concerning issues related to AIDS". [89]

Studies conducted in Europe and the United States indicated that parents' disclosure of their HIV seropositivity to their children was rare in

some areas[90] but ranged from 30[91] to 50 per cent elsewhere.[87, 89] Disclosure rates were higher when the children were older, but children who were also infected and living with the parents were less likely to be informed. Whether or not the children had been informed, at least half of the parents had made long-term plans for the future care of their offspring.[89, 90] Parents in Europe were more likely than those in other regions (especially Africa) to have made plans for future care, with such plans more common among parents that had known about their HIV infection for significantly longer than those without plans.[90] Children whose mothers had disclosed their seropositivity to them displayed lower levels of aggressiveness and negative self-esteem than did those whose mothers had not shared their diagnosis. For this particular sample, no negative effects were observed among young children to whom mothers had personally disclosed their HIV serostatus.[91] However, among a group of HIV-infected schoolchildren exposed to strategies ranging from full secrecy to full disclosure, around 75 per cent reported stressful experiences linked to HIV regardless of the disclosure pattern.[92] In the multi-centred European studies, uninfected parents and caregivers were significantly more likely than infected parents to want professional help with disclosure to an infected child. A group in New York has developed a successful strategy whereby disclosure of HIV status to a child is effected gradually over time, with a multidisciplinary team providing consistent support to the child. Continuous communication and negotiation between the members of the team, which includes the parents and other caregivers, are vital to the gradual process leading to complete disclosure.[93]

4.2.1 Adaptation and support

The families of individuals with HIV/AIDS are likely to undergo a process of adaptation that includes a redefinition of their relationships with and within the larger social environment and the avoidance of AIDS-associated stigmatization, as well as the delineation of new duties and responsibilities in the provision of care.[94] The four principal stages typically associated with family responses to AIDS are as follows: (a) life before AIDS; (b) the discovery of AIDS within the family; (c) life with a person who has AIDS; and (d) life following the death of that person from AIDS.[73] In a Mexican study, "families' discovery that one of their members was HIV-positive was most usually followed by a period of shock and adjustment. This involved a search for explanations that would make the situation more manageable. This quest varied in difficulty depending on whether family members were dealing with the problems posed by the HIV status of their relative alone, or whether they had to witness the double coming out of the affected individual. The moment of initial crisis is often characterized by a high degree of conflict during which the quest for explanation may pass through several stages of intra-familial blaming. This is a temporary but serious situation that can severely undermine the foundations of family solidarity."[73]

Among the motivations for adaptation and support within affected families is the desire to bear and care for children and to protect them from the discrimination, stigmatization and other hardships associated with HIV/AIDS. Studies conducted among peri-urban and rural households in Zambia indicated that "in spite of high levels of anxiety about AIDS in these communities, risk from HIV was not always associated with the act of conceiving children, nor did this association necessarily influence actual behaviour or family size preferences. In some cases, however, the threat of contracting HIV had led to a decision to have fewer children. Many also worried about leaving orphans for others to look after and the costs which might be incurred in taking over the care of orphans left by others." It was presumed that if a family affected by HIV/AIDS had fewer children, those children would receive better care once they were orphaned. In both the rural and peri-urban communities families shared a sense of limited control not just over fertility, but also over the wider economic and health environment.[95]

A study from Canada illustrates the complexity of the parent-child dynamic in families affected by HIV/AIDS. In the study, the

major themes expressed by HIV-positive parents caring for children who were largely free of infection included chronic sorrow, stress and burden, the need for normalization, stigma, secrecy, and problems of disclosure. Parenting represented an additional challenge in an already complicated life but was found to be a source of joy nonetheless. Additional themes that were identified included family life as precious time, the need for focused parenting, the parenting preparation needs of fathers, and the differences in roles and responsibilities in situations involving affected parents and infected children.[88]

Another study from North America "evaluated an intervention designed to improve behavioural and mental health outcomes among adolescents and their parents with AIDS". [96] A total of 307 parents with AIDS and their 412 adolescent children, randomly assigned to an intensive intervention or standard care control condition, received an initial assessment and were reassessed at least once annually over the next two years. "Adolescents in the intensive intervention condition reported significantly lower levels of emotional distress, of multiple problem behaviours, of conduct problems, and of family-related stressors and higher levels of self-esteem than adolescents in the standard care condition. Parents with AIDS in the intervention condition also reported significantly lower levels of emotional distress and multiple problem behaviours."[96]

The impact of HIV/AIDS on uninfected older people is rarely examined in connection with parental responsibility for the care of adult children with AIDS. In Thailand it is common for older parents to co-reside with their adult children and depend on them for support. It is also common for individuals with AIDS to move back to their communities of origin at some stage of the illness. Research results published in 2001 indicated that "two thirds of the adults who died of an AIDS-related disease lived either with or adjacent to a parent by the terminal stage of illness and a parent, usually the mother, acted as a main caregiver for about half. For 70 per cent, either a parent or other older-generation relative provided at least some care."[97]

Family caregivers may not always be the best equipped to support individuals living with AIDS. A California-based study among a sample of 642 caregivers for people with AIDS included both traditional family caregivers (mothers, spouses and other relatives) and non-traditional caregivers (friends and homosexual partners). The research findings demonstrate that "a number of factors and conditions appear to be relevant for caregiver support. For example, results indicate that network factors, including frequency of contact, conflict, and community integration, are importantly related to caregivers' perceptions of emotional support. There is also a trend suggesting lower emotional support among traditional family caregivers, relative to non-family caregivers, within gender categories."[98] A separate study found that "images of HIV and AIDS and dominant cultural values ... influenced the way in which the families of gay men reacted to the news that a son [had] HIV disease. Of particular importance in determining the form of such responses was the way in which the family had previously reacted to the news that one (or more) of their sons was homosexual. Such responses were closely linked to the behaviours the same family displayed later regarding the second coming out as HIV-positive or as a person living with AIDS."[73]

4.2.2 Rejection, limiting care, and domestic violence

As previously noted, fear of rejection is one of the primary reasons people with HIV/AIDS do not disclose their serostatus to family members. The actual incidence of rejection is relatively low, and when it does occur it tends to be linked more to pre-existing family relationships than to the disease per se; even then, it generally wanes over time.[22]

In certain settings, limiting the provision of care to a family member with AIDS or an AIDS-related illness is not uncommon. Some of the reasons are based on objective considerations such as the following: circumstances associated

with impoverishment including a lack of food (particularly that suitable for a patient) in the home and/or the lack of money to buy medications; conflicting or overlapping demands and responsibilities, including the care of children, work obligations (many mothers, wives and sisters must cultivate the land to procure enough food for the household), and the care of other sick relatives; and/or the illness of the sole or primary caregiver. Less frequently, care may be limited as a result of erroneous beliefs surrounding the cause and treatment of the disease, or denied because of the stigma attached to AIDS.[99] Another commonly encountered argument for limiting care is that the person will die anyway, so there is no point wasting money on drugs or food. Some terminally ill individuals request that their caregivers or others not try to keep them alive any longer because they are tired of suffering.[99]

Anecdotal reports suggest that some women face substantial risks when their partners or other family members learn that they are HIV-positive. Domestic violence or abuse are frequently cited among the fears of those who decline VCT or are reluctant to disclose their HIV status to their partners or other family members. While disclosure may induce domestic violence or abuse against women, this type of response more often represents an expression of a pre-existing pattern than a change in a relationship effected by HIV disclosure. In a study involving 336 HIV-positive and 298 HIV-negative at-risk pregnant women in the United States, disclosure-related violence did occur but was rare, and was not typically attributable to the serostatus of the victims.[100] In another study, though two thirds of the women had been afraid to inform others of their HIV status because of concerns about rejection, discrimination or violence, three quarters of the sample reported that they had received only supportive and understanding responses to their disclosure. However, a quarter of the women reported negative consequences following disclosure, including rejection, abandonment, verbal abuse and physical assault.[101]

4.3 Disclosure and responses outside the family

The struggle to avoid discrimination is often part of a broader consensus among all family members and not just a concern of the person living with HIV/AIDS. This explains the frequent existence of arrangements between the infected individual and his or her family whereby support is provided within the family circle so long as the individual's HIV status remains concealed from outsiders. In 16 sub-Saharan African countries, the recent DHS included an item on discriminatory attitudes among women. The individuals surveyed were asked to respond to questions such as whether a teacher who was HIV-positive should continue teaching in a school, and whether they (the respondents) would buy fresh vegetables from a shopkeeper who had AIDS. In three countries the same questions were asked of men, whose responses were similar to those of their countrywomen. In 12 of the 16 countries the majority of women expressed agreement with at least one discriminatory statement about persons living with HIV/AIDS. In half of the countries, the prevalence of such attitudes ranged from 65 per cent to more than 85 per cent (see figure VII). In seven countries* more urban women than rural women indicated their agreement with discriminatory statements, the reverse was true in five other countries,† and in the four remaining countries there was little difference between the two (see annex IV, figure I).

In a study from Ghana, individuals with HIV/AIDS were unsure about the reactions of their neighbours and others in the community, with most having no idea what they thought. This was observed to be at least partly attributable to the fact that people with AIDS tend to have very little interaction with those outside the family.[22] A study on marital stability among HIV-discordant couples in Thailand noted that fear of community rejection prompted a response of secrecy. Women who remained

* Angola, Botswana, Côte d'Ivoire, Guinea-Bissau, Niger, Senegal and Somalia.

† Burundi, Namibia, Swaziland, Uganda and Zambia.

married, and even those who had separated or were divorced from their infected spouses, feared stigmatization and rejection "if members of the community discovered that their husbands were HIV-positive. The women spoke of how they believed others would assume that they (the wives) were also infected and would thus reject them."[83]

Stigma and discrimination

"Images of AIDS invoke fears of contagion, disability and formidable death, and moral overtones directed toward drug use, sexuality and sexual identity and freedom. Responses to these images are both private and public, and have profound consequences for individuals whose lives have been touched by the disease, [including] both the person with AIDS and the family caregiver."[102]

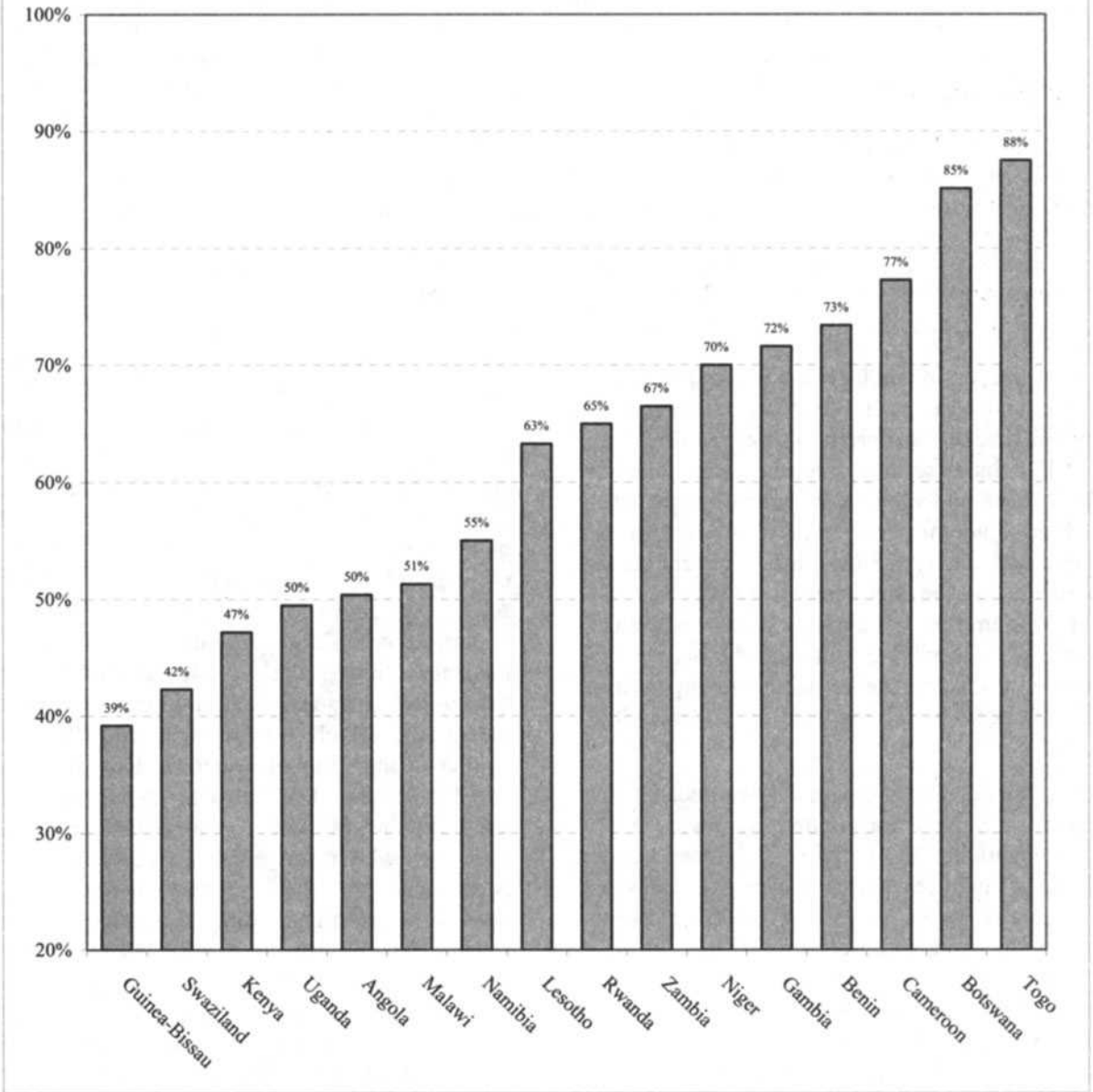
Reference is made in UNAIDS literature[103] to the established definition of stigma "as a 'significantly discrediting' attribute possessed by a person with an 'undesired difference'. Stigma is a powerful means of social control applied by marginalizing, excluding and exercising power over individuals who display certain traits. It is a common response to perceived threat when escape from, or destruction of, this threat is impossible."[104] Many societies reject or are hostile to certain social groups, including homosexuals, IDUs, sex workers and migrants. HIV/AIDS not only reinforces this stigmatization but has become a new discrediting group attribute. When such an attitude is internalized or passively accepted by some members of an affected family, it erodes the trust and communication component of that family's social and family capital. Fear of the consequences of self-identification within the family has created a silence that threatens the integrity and functioning of the family. Stigma-induced denial, rejection and secrecy undermine the ability of families to protect and mobilize social and family capital and resources to which they would otherwise have access.

The problems faced by those with HIV/AIDS are now fairly well documented. They include experiences of guilt, anger, grief, fear of abandonment, and potential economic hardship and marginalization owing to others' fear of infection and the stigma attached to the disease.[105] While not well quantified, the stigmatization and discrimination experienced by infected individuals and affected families are widespread and well documented, though the information available comes primarily from unpublished literature and anecdotal evidence obtained through interviews with project staff in South-East Asia (see box 3).[105, 106]

Stigma is such a powerful social force that it undermines the effective functioning and best interests of both infected individuals and their families. For example, despite having been counselled and told that HIV could be transmitted through breastfeeding, and that this practice might even undermine their own health, most HIV-positive mothers in Uganda prefer to breastfeed rather than use free infant formula.[107] Some studies from Uganda suggest that while the stigma attached to HIV/AIDS has adversely affected the treatment-seeking behaviour of those who are infected and the coping mechanisms of affected families, a more tolerant attitude is starting to emerge in the area, probably owing to improvements in counselling services and home-care schemes for those with AIDS. This lends some justification to the call for increased investments in counselling and community development focused on the provision of care for persons living with HIV/AIDS.[108]

Four types of AIDS stigmatization have been identified: "theologically-based blame, liberal concern for the health of those not afflicted, risk group problem, and civil rights. From the point of view of enlightened management of public health, the civil rights issue poses the most serious threat. The tension between the rights of the individual, who is at risk of exposure and condemnation because of stigma, and the rights of the rest of society interferes with the development of large-scale, effective public health programmes."[109]

Figure VII. Percentages of women aged 15-49 years who agreed with at least one discriminatory statement about persons living with HIV/AIDS, 16 sub-Saharan African countries, 2000-2003



Sources: National Demographic and Health Surveys or UNICEF-sponsored Multiple Indicator Cluster Surveys for Angola (2001), Benin (2001), Botswana (2000), Cameroon (2000), Gambia (2000), Guinea-Bissau (2000), Kenya (2003), Lesotho (2000), Malawi (2000), Namibia (2000), Niger (2000), Rwanda (2000), Swaziland (2000), Togo (2000), Uganda (2000/01) and Zambia (2001/02).

Box 3. Incorporating the AIDS stigma in cultural value systems

Over a relatively short period of time, the stigma of AIDS has been woven into the value systems of indigenous cultures in the developing world, where the terminology of blame and disgust generates a destructive social response to AIDS. In Thailand, the folk term *rok sang khom rung kiat*, or "disease of social loathing", is generally used by laypeople to describe AIDS; it is also referred to as the "woman disease". These terms are constructed "from two concepts: the belief that AIDS occurred many years ago as an STD, and that women who are regarded as promiscuous or are prostitutes (*Ying Sopanee*) are a reservoir or source of infection. ... A disease of bad people (*rok khong khon mai dee*) and a disease of karma (*rok khong khon mee kam*) are also used in the folk category in association with religious beliefs. ... The terms also indicate moral behaviour. The less likely people are to be involved in sex or any risk behaviour, the greater their (good) karma and the less likely they are to contract HIV. Finally, ... AIDS may be referred to as a disease of bad blood or poison blood; this term is mainly used by patients."

Sources: P. Songwathana and L. Manderson, "Perceptions of HIV/AIDS and caring for people with terminal AIDS in southern Thailand", *AIDS Care*, vol. 10, No. 2, supplement (June 1998), pp. S155-S165.

Procrastination and inaction among political, religious and other social leaders in addressing the stigmatization experienced by people with HIV/AIDS have seriously compromised public health efforts and effectively helped perpetuate the three epidemics. By failing to act in a decisive and timely manner, these leaders have also facilitated the continued stigmatization of affected families, leaving them isolated, unsupported and unable to access the necessary information or to secure the means to cope with the challenges of caring for a person with HIV/AIDS.

In some developed countries, two decades of AIDS activism have contributed to a measure of destigmatization. In certain developed and developing countries efforts to remove or lessen the stigma attached to HIV/AIDS have been supported to varying degrees by political leaders and celebrities. In the context of the family, these efforts have created an enabling environment for AIDS family caregivers to "go public", letting others know that they are caring for a person living with HIV/AIDS. "Specifically, going public [has] entailed selecting appropriate persons and audiences to tell, formulating approaches to communicating information, and considering the risks and benefits of the possible choices. The description of going public as an AIDS family caregiver details the assertiveness involved in political action and social change, contrasted with the isolation and secrecy involved in maintaining relationships with others under the condition of a stigmatizing illness."[94] A United States study on going public took particular note of "the phenomenon of 'guilt by association'. Because of their close relationship to a person with AIDS, caregivers were obligated to share the stigma of AIDS and were likewise discredited. Findings from [the] study emphasize the tremendous personal suffering experienced by caregivers, which was associated with AIDS stigma in the form of rejection, loss of friends and harassment. Data also revealed the strong commitment of many caregivers to social activism, which ranged from participating in educational efforts to marching in demonstrations. The rationale for the apparent increased activism among AIDS family caregivers compared to other groups of caregivers is explored. Going public highlights both the personal suffering and social manifestations of AIDS, significant issues to consider in planning health services for the AIDS epidemic."[102]

The many grass-roots non-governmental organizations (NGOs) that have sprung up in developing countries to address HIV/AIDS-related concerns constitute evidence of a growing trend towards culturally adapted

activism and efforts to promote destigmatization.[110, 111] The AIDS Support Organization (TASO) in Uganda is one such NGO set up to assist individuals infected with or affected by HIV, providing counselling, social support, and medical and nursing care for opportunistic infections. The counselling services have helped clients and their families cope more effectively with the challenges accompanying HIV and AIDS. An evaluation of the Organization's services indicated that 90.4 per cent of the clients had revealed their serostatus, and 57.2 per cent had consistently used condoms during the previous three months. As a result of counselling, over half of the clients (56.9 per cent) had made plans for the future, and 51.3 per cent wished to make wills. There was a high level of acceptance of people living with AIDS by families (79 per cent) and the community (76 per cent). Through counseling and the provision of medical care and material support for clients and their families, TASO has effected changes in people's attitudes, knowledge and lifestyles. In particular, the Organization has demonstrated a strong capacity to overcome four problems that undermine AIDS care in most places: (a) revealing one's HIV serostatus to significant others; (b) accepting individuals with HIV/AIDS in the family and community; (c) seeking early treatment; and (d) combining prevention and care.

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CHAPTER 5
CARE, ILLNESS AND DEATH IN THE FAMILY

5.1 Caregivers and caregiving

Care, in the present context, refers to family members contributing time, attention, support and skills to meet the physical, mental and social needs of others in the family. Caring capacity relates to the ability to mobilize and apply family and social capital in the form of human, economic and organizational resources for the benefit of the family and its members. It therefore involves issues of knowledge, time and control over resources. The responsibility for providing care commonly falls disproportionately to women.

It cannot be assumed that the adult members of families affected by HIV/AIDS will agree to provide care for infected relatives. The readiness to offer such assistance varies widely among countries (see figure VIII) and to a lesser extent between urban and rural areas. There is a small but consistent difference between men and women in terms of their willingness to provide such care. Men and women in urban settings are generally more willing than those in rural areas, and there is a slightly higher proportion of men than women indicating that they are prepared to furnish the necessary care. The less enthusiastic response among women may reflect a higher degree of prejudice, or it may simply represent a more realistic understanding of the level of commitment required since they, rather than the men, are the ones most likely to be called upon for such care.

HIV/AIDS has a profound and disruptive impact on the family. The effects of the illness alone are such that the level and duration of care required far exceed the corresponding demands associated with most other diseases. Often such care—for both infected individuals and those they leave behind—is provided by family members well past their prime or not yet matured, particularly after the death of one or more productively active adults.[112] The difficult situation into which caregiving relatives are unexpectedly thrust is exacerbated by the potential risks of intrafamily transmission of the infection, the stigma attached to HIV/AIDS, and the threat of discrimination from "guilt by association".

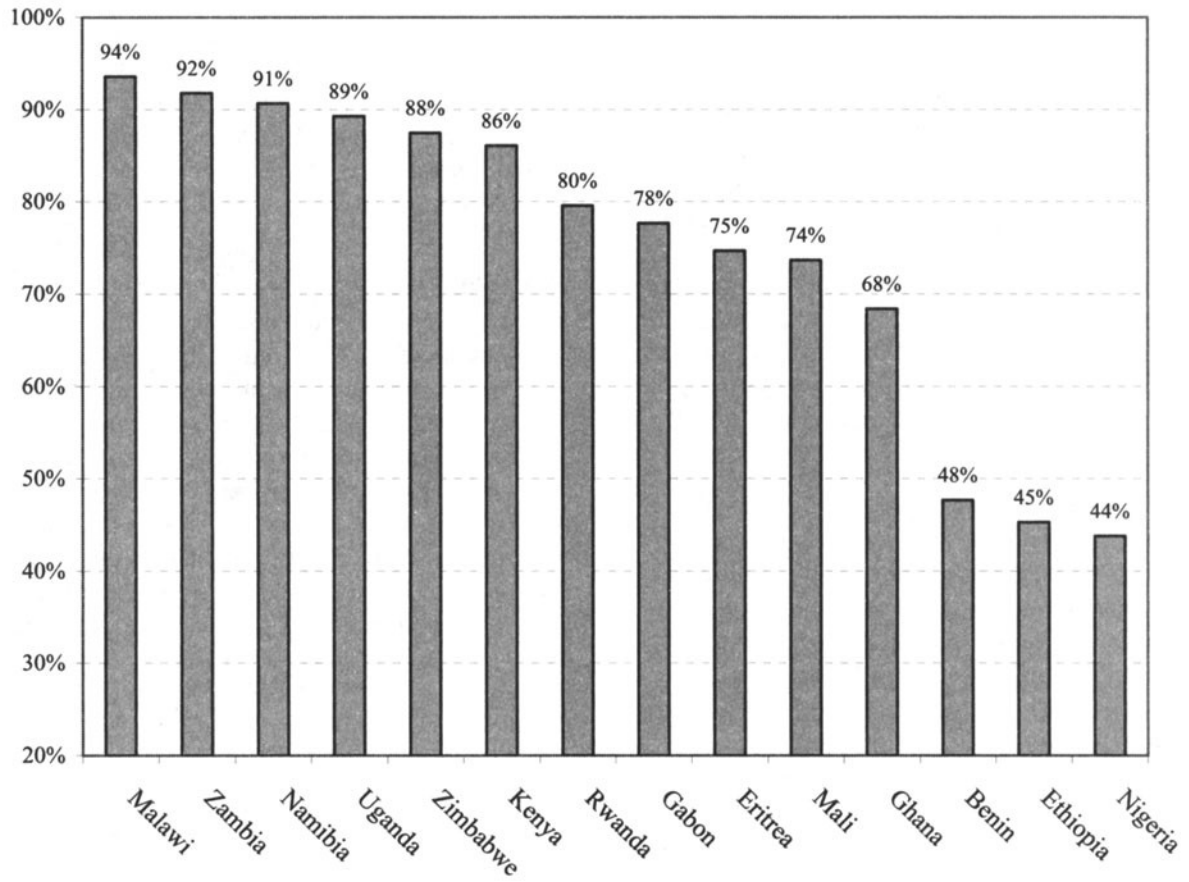
Providing care for individuals with HIV/AIDS is "an intense, emotional, and powerful experience filled with pride and enrichment, and conversely, with anger and disillusionment".[113] Coping with HIV infection, AIDS and subsequent death places a particularly heavy burden on families and stretches the limits of their caring capacity. Some have observed that the impact of AIDS on households is not like that of disasters such as drought, famine or war because the progression of the illness (from the onset of HIV/AIDS to death) "is gradual and incremental and occurs over a period of at least five years".[78] Under such circumstances the different forms of family capital are constantly eroded. Relationships are strained, resources are consumed, and family resiliency is challenged. At the same time, the willingness and capacity to provide care is a positive measure of the strength of family bonds, a major component of family capital.

5.2 Caregiving support

In developed and developing countries alike the health systems are unable to reach all individuals with HIV/AIDS or to meet the needs of those requiring help and support. Consequently, the assistance of families, however defined, is essential in the care of people living with the disease. The following issues have dominated the research and evaluation of caregiving support based on a medical model of care:

- Identifying the needs of the person living with HIV/AIDS that are to be met within and by the family;

Figure VIII. Percentages of women willing to care for a relative with AIDS at home, 14 sub-Saharan African countries, 1999-2003



Sources: National Demographic and Health Surveys for Benin (2001), Eritrea (2002), Ethiopia (2000), Gabon (2000), Ghana (2003), Kenya (2003), Malawi (2000), Mali (2001), Namibia (2000), Nigeria (2003), Rwanda (2000), Uganda (2000/01), Zambia (2001/02), and Zimbabwe (1999).

- Improving the capacity of the caregiver(s) to meet those needs.

Studies are starting to address the burden of HIV/AIDS caregiving on the primary provider; however, little has been written about the overall burden placed on affected families within this context, or about their specific caregiving role and functions.

The provision of care for people living with AIDS is characterized by wide variations based on the structure, beliefs and recognized obligations of families. As noted in one small study conducted in Ghana in 1992, AIDS caregiving in the traditional African setting rests almost entirely with blood relatives, including parents, siblings and/or children. Among those interviewed for the study, only 9 per cent were receiving care from their spouses, and 11 per cent were caring for themselves; in none of the cases was an infected woman being cared for by her husband.[22] Among some groups in Uganda, intergenerational care has been essential for survival and the prevention of HIV infection.

To be effective, caregivers must come to terms with the disease within the social and cultural contexts of the family and immediate community. Outside of the formal health-care

system they may be assuming responsibility for care and treatment decisions, often relying on a combination of traditional, indigenous, spiritual/religious and modern medical options.[114] The pattern of moving between modern and traditional medical systems appears to be more common in AIDS situations than in circumstances in which family members have died from other causes.[115] Families providing care often experience misgivings and feelings of fear, shame and embarrassment. A family may isolate the person with AIDS and, for example, separate that individual's eating utensils and items used for personal hygiene from those of the rest of the family. In many cases the Government provides little or no assistance, and families affected by HIV/AIDS are concerned about the fact that they must bear the full burden of care. As AIDS progresses, the likelihood of family neglect increases. In the Ghana study 5 per cent of the hospitalized AIDS patients had been abandoned by their families.[22]

There is an obvious need for information, training and increased awareness among those responsible for the family-based care of individuals with HIV/AIDS, particularly in the light of existing social and institutional barriers and the limited knowledge and experience of caregivers. Affected families often require material assistance, but they also need moral and practical support in the form of encouragement, reassurance and sensible advice on how best to provide adequate care for their sick members.[99] Caregivers benefit from periodic respite as well.[116, 117]

Family caregiving can be divided into three stages corresponding to the progression of HIV/AIDS in the infected individual. Some of the challenges and requirements associated with these stages are summarized in the following:

- From the moment of HIV disclosure, those family members who have been informed need to receive the kind of assistance that will allow them to provide emotional and psychological support to the person living with HIV/AIDS, facilitate the family's adjustment to the new situation, and stimulate the process of future planning for the well-being of all family members;
- When the person with HIV/AIDS is no longer able to carry out his or her expected functions within the family, the process of family capital erosion begins. Factors contributing to this erosion include increased expenditures for health care, the decline in the infected individual's productive and economic activities, and the slowdown in family capital accumulation that comes with the redefinition of roles to ensure family survival, a familiar example being the withdrawal of children from school to allow them to engage in productive activities;
- When the person living with HIV/AIDS is no longer able to accomplish everyday tasks, leading to an even greater diversion of family capital to direct care, further contraction of family capital occurs and the likelihood of exposure to HIV/AIDS discrimination increases.

The family network is often the critical element in supportive care. In a study of more than 200 people living with AIDS in an urban setting in North America, fewer than two sources of close support were available on average. Women most often relied on their children for help, men who had contracted HIV through heterosexual contact tended to rely more on traditional family sources, and men who had become infected through injecting drug use or sexual contact with other men relied almost equally on family and friends. Barriers to support included interpersonal costs, lack of access, lack of acceptance, lack of intimacy, negative interactions and fear of disclosure.[118] The study concluded that comprehensive network assessments were essential to determine the full scope of support resources available to each individual with HIV/AIDS, and that the dynamics of the caregiving experience should be identified so that interventions could be designed and adapted to provide direct and effective support for those caring for family members with HIV/AIDS.[113] Screening and educational initiatives that provide information

about family conflict resolution and the course and transmission of HIV may help to minimize barriers to care,[118] and may be an absolute necessity in some instances to mitigate the adverse and sometimes violent intrafamily reactions to the disclosure of HIV seropositivity.

The magnitude of HIV/AIDS and the speed with which the epidemic has developed in many areas has severely strained the normally evolving adaptive coping capacity of families, particularly those in traditional societies, producing a crisis situation in many settings.[119, 120, 121] Migrant families, surrounded by a different culture and often lacking access to the social capital of their communities of origin, face additional challenges in this context, and research findings indicate that they experience greater stress when confronted with HIV/AIDS than when dealing with chronic illnesses unrelated to HIV.[122] Among the caregiving challenges noted in a review of the situation in south-eastern Brazil were the lack of orientation and supporting materials, the lack of transportation, and the unavailability of people to provide respite for caregivers. Family caregivers experienced a range of strong feelings and emotions including the fear of infection, revulsion, pity, and powerlessness in the face of death.[120]

The coping capacities of households and families vary widely. Extended families and clans in African societies have extensive systems of treatment and patient management that can be used in dealing with those who have AIDS.[112] However, many families lack experience in handling the unique challenges associated with HIV/AIDS care. Despite efforts to disseminate information on home care, the lack of accurate knowledge remains a common problem among family caregivers. In areas of Botswana where a structured home-based programme was initiated and included counselling, pastoral care and training, as well as community involvement in providing care, the authorities noted "an alarming rate of readmission to hospital of patients with numerous complications, suggesting poor quality care at home".[119] Anecdotally, instances of older caregivers being diagnosed as HIV-positive were noted, suggesting transmission might have occurred during the process of caregiving, possibly through open wounds. An assessment of awareness levels among families providing care for their terminally ill relatives at home "indicated that families lacked knowledge and skills for providing appropriate care, they were not aware of the resources available, and they lacked professional and material support. The study recommended that a good referral and follow-up system should be in place for effective implementation of home-based care, with appropriate procedures for monitoring and evaluation."[119]

In many traditional societies there are cultural, economic and logistical reasons for home care. As family caregivers play an increasingly important supporting role in the everyday lives of HIV-infected family members and become more involved in different aspects of counselling and caregiving, a partnership is established with the health-care professionals responsible for other dimensions of the patients' care. Both family caregivers and medical professionals face particular difficulties and have different needs and expectations that must be met in order to optimize the quality of care provided to individuals with HIV/AIDS.[123] Maintaining or improving the quality of life for those with HIV or AIDS requires the provision of culturally congruent nursing support for affected families.[124] In Thailand, an NGO-sponsored project set out to identify the educational needs of home-based AIDS caregivers. Within Thai culture, a specific family member is recognized as the "natural helper" and is responsible for the care of sick family members. The natural helper has a privileged place within the family and facilitates the continuity of care between the health system and the family. An evaluation of the home care provided to those living with HIV/AIDS indicated that these helpers were unprepared for such care, though they were thought to be well suited to dealing with other illnesses.[121] Here, too, developing a process of socially coherent and adapted communication between the family and the health-care system was seen as a critical

step in improving the provision of care by the family.

Women as caregivers

In virtually all societies and in nearly all affected families, women are the primary caregivers in the home-based care of individuals living with HIV/AIDS. For most of the developing world, and to a lesser extent in developed countries, that care is intergenerational, with mothers most often being the primary caregivers for adult children and grandchildren. Depending on the local cultural patterns and living arrangements, either a female partner or a sister is the second most frequent caregiver in a majority of developing countries.[99, 125] In the nuclear family, children are often the next most common caregivers. Members of the extended family may also participate in the provision of care and support. The contribution of friends and neighbours to primary caregiving and of other relatives as secondary caregivers is small.

A study undertaken in an urban setting in Thailand revealed that the caregivers were mainly mothers and wives, who considered it their place and duty—and morally beneficial—to care for adult children or husbands sick with AIDS.[125] In a study from a rural area of Uganda in which the mother-sister/wife pattern of care prevailed, nearly half of the families lacked any additional assistance. The extra help some families received was almost invariably provided by another female relative. In a few instances female counsellors prepared food for the patients, cleaned their surroundings, and washed their bedclothes.[99]

In Uganda, care tends to be home-based because of the inadequacy and expense of formal health-care services and facilities and because of the lack of medication and poor staffing levels in health units. One study carried out in the south-western part of the country confirmed that women were responsible for the bulk of caring activities but questioned whether female informal caregivers were in a position to cope effectively with long-term illness in the home. There were indications that "many women, particularly in female-headed households, did not own or have direct access to the necessary finances to meet the family's health-care needs as expected of them. Although relatives and friends were seen as a valuable resource, because of poor household proximity and financial constraints they were not always in a position to offer or provide assistance. The women also identified themselves as responsible for a variety of home and agricultural tasks; such activities were frequently disrupted by illness episodes. As women take on the additional burden of care for those with HIV/AIDS an inevitable conclusion is that their resources, both social and economic, will not be adequate."[126]

Even in developed countries, where reliance on medical models of care is much greater, women provide substantial support to those with HIV/AIDS despite the fact that many are already overburdened with family and work commitments. Although the caregiving characteristics of these women differ according to their relationship to the person living with HIV/AIDS (mother, wife, sister or friend), there tends to be a high degree of similarity with regard to both the amount of care provided and its impact on the caregiver's health.

When the use and financing of health services for people living with HIV/AIDS are studied, the role of female family members as caregivers is largely unacknowledged, virtually disappearing as a factor or variable in analyses, and their contributions become socially invisible. The role typically assumed by women in this context is subsumed under the rubric of "community care". This all-too-common health services perspective exists in stark contrast to the largely disregarded realities of caregiving by women relatives.[127]

5.3 Caregiving for adult children dying from AIDS and for their surviving children

The number and proportion of grandparent-headed family households that include children (with or without their parents) have been rising steadily in the United States since 1970, even in the absence of significant increases in the number of orphans. Between 1970 and 1992 the

largest increase in grandparent-headed family households was among those in which one parent was present; from 1992 to 1997 the greatest increase was among those with neither parent present.[128] Family structure affects a grandchild's well-being. Children in grandmother-headed households with no parents present are most likely to be poor and to have received public assistance, and those in households with both grandparents but no parents present are most likely to be uninsured.[128]

Throughout the world grandparents are playing a greater role in the provision of care in families affected by HIV/AIDS, assuming responsibility for their infected adult children and their (eventually orphaned) grandchildren. Large numbers of people with AIDS return to their communities of origin at some point during their illness and, in a reversal of the traditional support relationship between older persons and their adult children, are cared for by their parents.[125, 129, 130] Grandparents (especially grandmothers), maternal great aunts, and occasionally other relatives of the same generation have become surrogate parents to children and adolescents who have lost their natural parents to AIDS or whose parents are too ill to function as their primary caregivers.[131, 132] Such circumstances allow greater integration of the older generation into the family, offering them the pleasures of parenting and giving them a strong sense of usefulness; however, caregiving responsibilities are substantial in this type of situation and represent a drain on the energy, time and limited resources of the grandparents.

Older surrogate parents must cope with both the stress of caregiving and the attendant risk of neglecting and compromising their own health. Often they consider their health "fair" or "poor", and most report having insufficient time to attend to their own health needs.[133] In the United States, older grandparents raising children orphaned by AIDS are confronted with internal and external barriers to self-care and support, including the lack of child health insurance and respite care, caregiver depression, and the denial or neglect of health problems.[117] Isolated by the demands of caregiving and by the AIDS stigma that touches even uninfected family members, custodial grandparents are at risk not only for chronic conditions and stress-related somatic complaints, but also for health problems brought on by neglect. They represent the "hidden patient".[117]

Despite the differences in family structure and cultural background, African American and Hispanic grandmothers acting as the primary caregivers for their HIV/AIDS-infected grandchildren in the United States were shown in a study to be more alike than different, as reflected in their common perspectives on such issues as upholding the primacy of the family, living in the child-centred present, being strong as mature women, and living within a constricting environment.[134] Grandparents providing care in families affected by HIV/AIDS in developed countries face many of the same challenges and appear to share similar concerns and priorities within the caregiving context, which has positive implications for the development of support initiatives aimed at this group.

In a random sample of families registered at three pediatric clinics in low-income neighbourhoods with a high incidence of female HIV/AIDS in New York City, parents were not the caregivers in 11 per cent of the 1,375 families with 2,445 children aged 12 years or under. In 8 per cent of the families the caregivers were grandmothers, half of whom were aged 55 or over, and one fourth of whom were at least 60 years old. Most of these women were caring for more than one child. One per cent of the children were in foster care. Given the greater levels of stress associated with caregiving later in life and the increased likelihood of poor health among older persons, low-income African American and Hispanic individuals, older surrogate parents from these communities represent a population potentially at high risk for health problems—a population whose needs may go unrecognized and unmet. Many grandparents continue to be caregivers well into their sixties, seventies or even eighties.

Health and social services for older persons must be coordinated with the corresponding services for children in order to promote the development of effective programmes for these families.[135]

While many of the challenges for grandparents and older caregivers in the developing world may be similar to those faced by disadvantaged groups in the developed world, the nature, magnitude, and order of priority of the obstacles encountered are likely to be very different. Culturally and historically, adult children have constituted the primary source of "social security" for older parents in societies lacking public sector social safety nets or institutions. The poignancy of bereavement following the premature death of an adult child is magnified, and the loss of resources and decline in the quality of life accelerated, as the death of adult children from AIDS occurs repeatedly in many families in the developing world. It becomes increasingly difficult for older caregivers to ensure a "good death" for their adult children under these circumstances,[136] and particularly difficult to meet the needs of the surviving grandchildren. The term "good death" has been defined in both developed[137] and developing country settings. In a study from Uganda, a death is considered "good" if it "occurs when the dying person is being cared for at home, is free from pain or other distressing symptoms, feels no stigma, is at peace, and has [his or her] basic needs met without feeling dependent on others".[136] Currently there are no estimates, but only anecdotal descriptions, of the incidence, prevalence and average size of "grandparentalized" families, and of the burden or extent of family capital loss suffered by such families.

5.4 The costs of caregiving

When the costs of HIV/AIDS care are calculated, the caregiving contributions of the family and of other social support networks are either ignored or assumed to have no economic value. This assumption of "free" care has been challenged in several studies that have focused on the labour and economic aspects of family home care and have assigned it a monetary value.[138, 139, 140] A study conducted in North America revealed that caregivers spent an average of 8.5 hours a day performing personal care and household tasks for individuals with HIV/AIDS. The most common activities were providing companionship, running errands, and handling food- or meal-related arrangements. Gender comparisons suggested that women performed more hours of housework than did men, but that both provided similar types of personal care for approximately the same number of hours. Using a market valuation method, the annual value of unpaid care, including housework, was calculated to be US$ 25,858 for each person living with HIV/AIDS.[138]

In a study from New Zealand the private costs both for individuals with HIV/AIDS and for family/household/informal caregivers were measured and assigned a value. A small group of people living with HIV/AIDS was followed prospectively. Private direct costs rose steeply as the illness progressed, increasing from around US$ 100 per month for asymptomatic HIV-infected individuals to around US$ 400 per month for those with AIDS. Both indirect costs (foregone income) and intangible costs were considerable and burdensome as well.[139]

A study conducted in rural and urban areas of Zimbabwe examined the quality and overall costs of community home-based care for HIV/AIDS patients and the care-related costs borne by the family. Community caregivers spent an average of 2.5 to 3.5 hours a day on routine patient care. Home visits in an urban setting were estimated to cost between 129 Zimbabwe dollars (Z$) and Z$ 183 (US$ 16 to US$ 23). For the rural schemes, the cost of a home visit ran between Z$ 313 and Z$ 343 (US$ 38 to US$ 42). A large proportion of the cost did not translate into tangible benefits, as approximately 56 to 75 per cent of the total was spent getting to the patient. The cost of a home visit in a rural home-based care programme corresponded to the cost of 2.7 inpatient days in a district hospital. The family's payment for the care of a bedridden AIDS patient over a three-month period was estimated at between Z$ 556 and Z$ 841. The programme costs were high, leading to a reduction in the frequency of visits

and the consequent transfer of a larger share of both the burden and the cost of care to the patients and their families.[140] In Tanzania a comparison of household terminal illness expenditures for AIDS and other causes of death indicated that there were higher expenses associated with AIDS, and that the direct medical costs were 1.5 times greater than the funeral costs; it was also noted that the medical and funeral expenses together exceeded the average household income.[115]

5.5 Stigma and risk perceptions in caregiving

A study carried out in southern Thailand revealed that rural residents were more likely than those in urban settings to perceive themselves as being at risk of infection in caring for individuals with HIV or AIDS, and were less likely to provide care if their relatives or friends were afflicted with either. In focus group discussions, women in both urban and rural areas demonstrated a considerable lack of awareness with regard to the likelihood of HIV/AIDS transmission during the process of caregiving. A significant number of women were convinced that a person who took care of an AIDS patient would become infected as well, possibly by touching the patient's blood, clothes or personal belongings.[105] In this context, "women reported a greater precaution in contact with people who showed visible symptoms, which they regarded as indicative of high infectivity. So, they were reluctant to get close to symptomatic patients and to give care or help, unless they were closely related to the patient, e.g., within the immediate family. It is interesting that women living in areas of known AIDS cases had a greater fear of contact compared to those living in areas without AIDS cases. This is partly because AIDS patients whom they have seen had developed skin lesions. However, rural people had a greater fear of contact than urban people as a result of uncertainty and misunderstanding of transmission of and susceptibility to AIDS."[105] Because of their "better access to AIDS information and direct experience of seeing AIDS patients in hospital, urban people were more likely to understand HIV transmission and risk",[105] and had a higher proportion of correct responses to relevant questions than did rural people. The study noted that AIDS posters were rarely displayed in villages, and village residents typically heard and learned about AIDS only indirectly, from sources such as radio and television. Gossip and rumour were other important means by which information was transferred from household to household and from one village to another, and were often misleading or incorrect. Risk perceptions of AIDS varied according to the residential setting. "Both women and men in rural areas perceived themselves to be at lower risk than urban people and did not see AIDS as a major problem. They believed that accidents were the main cause of illness and death. In contrast, urban men saw themselves as being at lower risk than rural men because of their greater experience and sophistication;"[105] rural people were perceived to be both attracted to the city and lacking experience in modern society, placing them at higher risk. Although the AIDS patients registered at the two central hospitals in the south were mainly from urban areas, this was thought to be a reflection of the poorer access to health-care services and higher likelihood of underdiagnosis in rural areas rather than an indication of any real bias in infection.[105]

An in-depth study of stigmatization was undertaken among a small group of mainly African American older women serving as informal caregivers for adults and children with HIV, and the results indicated that the women rarely experienced any overt manifestation of HIV-related stigma, primarily because they had not disclosed the presence of HIV in the family to outsiders. They had not given anyone the opportunity to ostracize or judge them. However, there was evidence that HIV-related stigma was internalized, so that disclosure decisions were based on the anticipation of censure. There was also evidence of associative stigma and of stigma management, highlighting the need for increased awareness of the necessity to provide support to the often invisible population of stigmatized and isolated HIV-affected caregivers.[141]

5.6 Parenting and childcare

Among families affected by HIV/AIDS, careful consideration of effective childcare policy options and related personal choices begins before pregnancy with the decision to become pregnant, continues during pregnancy with the decision to accept VCT before delivery and drug therapy to prevent MTCT, and is sustained after delivery with decisions regarding infant feeding* to optimize the chances of survival of the newborn.

Depressingly, the resources and infrastructure requirements for VCT and the prevention of MTCT are lacking in those areas of the developing world most devastated by the epidemics. The majority of children infected with HIV acquire the disease from their mothers. With the availability of new treatment regimens, "HIV-positive children are living longer, often into their school years, and most are able to live at home."[116] It is not uncommon to find multiple family members with HIV. Parents and other caregivers "are frequently overwhelmed by depression, anxiety and grief, and urgently need childcare assistance."[116] In countries with developed child welfare services, "finding childcare is difficult since families are often reluctant to disclose the AIDS diagnosis to potential childcare workers."[116] Because of the social and psychological vulnerability of children, policy makers and families affected by HIV/AIDS must confront the issues of HIV disclosure and stigmatization as priority concerns in controlling the epidemic of fear and in ensuring the well-being of children affected by HIV/AIDS.

The issues of parenting, childcare and HIV/AIDS may be considered in the context of the following three scenarios: (a) infected parent(s) and affected but uninfected child(ren); (b) infected parent(s) and infected child(ren); and (c) uninfected surviving parent or other family caregiver and infected child(ren). The stresses and needs of children, parents, and other adult family members are different for each scenario and vary depending on the cultural context, economic circumstances, the existence and capacity of social welfare and other support institutions, and the strategies chosen by the affected family to minimize its loss of social and family capital. The development and implementation of cross-sectoral policies in areas such as family and child welfare, women's affairs, health and education are needed to protect those children and families whose lives have been touched by HIV/AIDS.

Studies in developed countries indicate that mothers infected with or affected by HIV exhibit high perceived stress and low efficacy with regard to managing parenting demands in association with the disclosure of seropositive status. In one study, the length of time since diagnosis, psychological adjustment, AIDS knowledge, and health status as indicated by CD4 count were all factors unassociated with disclosure. Half of the mothers in the study met the diagnostic criteria for a psychological disorder in the preceding year, most commonly post-traumatic stress disorder and major depression.[142] Other studies have examined not only the psychological condition of HIV-positive mothers but also their home lives and how these women function as caregivers with a chronic illness. Among a group of 135 HIV-positive symptomatic or AIDS-diagnosed mothers of young children, the mean level of depression was elevated and was associated with poorer cohesion in the family and poorer family sociability. Depression was also associated with the mothers being less able to perform their regular duties; children of the more depressed mothers had increased responsibility for household tasks.[143]

Despite the existence of a child/social welfare tradition and accompanying institutions and legal frameworks, children in families affected by HIV/AIDS may fail to have their needs met owing to a lack of knowledge on the part of the family, the fear of stigmatization, or gaps in the social safety net. In a multi-centred study of 478 HIV/AIDS-affected families with

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* The issue of infant feeding is addressed in a subsequent section.

at least one child, the most common primary caregivers for all children within a family unit were the mother alone (46 per cent), one or both grandparents (16 per cent), and the mother and father jointly (15 per cent). Fewer than 10 per cent of all children were cared for by others. As the number of children increased, mothers were less likely to be the primary caregivers.[144] In another study, only a third of the mothers knew about or used childcare assistance services. It has been speculated that the parents' fear of losing the guardianship of their children is at least partially responsible for the failure to use such services.[145] Other studies indicate that when women die, older grandmothers frequently become the guardians of the children, despite the fact that these older people are often in poor health as well.[135] It has been suggested, based on an analysis of these studies, that grandparents and fathers might require special support services aimed at relieving some of the childcare burden, helping children deal with their mothers' illness and eventual death, and assisting HIV-positive children in accessing health care.[144] Grandparents would also require support to help them deal with their own health and nutritional needs, as well as their grief over the loss of their adult children.

A Canadian study examined the parenting needs of 105 mothers and fathers living with HIV/AIDS, most of whose children were uninfected. As mentioned previously, many of the parents experienced chronic sorrow and stress, a sense of added burden, and concerns relating to stigmatization, secrecy, and disclosure. They allowed that being a parent represented one more challenge in an already complicated life but sought to achieve a certain degree of normalization, noting that parenting constituted a source of joy. Several critical themes emerged from the study, including family life as valued and precious time; the need for more focused parenting; the various effects of HIV/AIDS; the parenting preparation needs of fathers; and the different responses called for in scenarios involving affected parents and infected children.[88]

5.6.1 HIV-infected children

Providing care for a child who is infected with HIV is challenging for the caregiver and affects the entire family system. As noted above, new therapies have made it possible for HIV-positive children to live longer, often into their school years, and most are able to live at home. Parents and other caregivers are frequently overwhelmed by depression, anxiety and grief and are in urgent need of childcare assistance; however, seeking, finding and obtaining such assistance may be difficult since families tend to be reluctant to disclose the HIV or AIDS diagnosis to childcare workers. In-home respite care programmes represent a critical adjunct in supporting families affected by HIV/AIDS, and are of direct benefit to those caring for infected children. Such programmes are generally developed and coordinated through a hospital's social work and volunteer departments, and include strategies for recruiting, training and supervising volunteers that are willing to provide respite care for families with HIV-infected children.[116]

The limited research available, which is largely from developed countries, indicates that the caregiver's HIV status and socio-economic circumstances are more likely than the child's HIV status to affect the level of stress and coping capacity of the caregiver. While research has demonstrated that social support has the potential to buffer stress and facilitate coping among caregivers, an experimental study showed no difference between the intervention and control groups until the serostatus of the caregiver was taken into account.[146] In another study, stress levels and coping capacities among caregivers of HIV-positive children and among caregivers of healthy children were measured and recorded. Equally high rates of psychological distress were observed in both groups. "Caregivers who reported high levels of daily stress and emotion-focused coping styles tended to report more psychological distress."[147] The caregivers who experienced more psychological distress also reported more internalizing and externalizing behaviour

problems among the children in their care, regardless of whether the latter were infected or uninfected, suggesting that the impact of poverty and environmental stresses (such as poor housing and sanitation and the lack of safety and security in the community) was more important than the children's serostatus in the caregivers' adjustment.[147]

In a small study of fathers of children with HIV/AIDS, more than half of the men experienced significantly elevated levels of both parenting stress and psychological distress in comparison with standardized norms. Nearly all reported the need for services including gender-specific support groups, help with discipline, disease management, and assistance in planning for the future.[148]

In the developing world there are only a few studies dealing with the disclosure of HIV status to children, parenting infected children, or counselling caregivers. A report on the findings of one such study,[149] conducted as part of a series of long-term studies in Uganda, included a number of relevant observations (see box 4). It should be noted that none of the observations has been verified or studied in other developing country settings.

Box 4. Observations on parenting and on counselling caregivers
for HIV-infected children in rural Uganda

- Acceptance of the child's HIV-positive status is correlated with the parent's readiness to accept care for the child and comply with the advice offered by health-care counsellors;
- The knowledge that the child is infected causes the mother great emotional stress. Those who are desperate or depressed find it difficult to follow the proffered advice;
- The mother may neglect to take care of the child if she believes that the child may die at any moment;
- Mothers experience stress deriving from the fear of being unable to care for their children; those mothers who are living with HIV or AIDS worry about what will happen to their children when they (the mothers) become weaker, fall sick or die;
- Mothers and other caregivers experience emotional stress as a consequence of material problems or poverty; there may not be enough money available to buy medicines, pay school fees or ensure proper nutrition;
- Caregivers express concerns about the lack of money for transportation to attend counselling sessions, the caregiver or child being too weak to travel, and the lack of sufficient time for such outings; they appear to be unsure whether regular counselling visits are useful;
- Many caregivers seem unable to implement the options presented by counsellors, possibly because they lack the money, materials or facilities (such as land or a clean water hole);
- Many women are afraid to tell their husbands, their relatives and community members that they are HIV-positive;
- Many mothers with HIV/AIDS worry that family members will not be able to care for their children as they do because of financial problems (which is often the case when children are left with grandparents), or because the children are not their own;
- Sometimes an infected mother tries to prepare for her death and ensure the family's security by saving some money or by building a house.

Source: C.N. Brouwer and others, "Psychological and economic aspects of HIV/AIDS and counseling of caretakers in HIV-infected children in Uganda", *AIDS Care*, vol. 12, No. 5 (October 2000), pp. 535-540.

When parents do not accept the fact that their children are seropositive, they will not be motivated to follow the advice offered by counsellors or doctors, and are unlikely to depressed often find it extremely difficult to take action with regard to the items discussed. "The readiness of a caregiver to return for control or follow-up seems to be defined in a similar way. Denial and despair may prevent caregivers—especially parents—from adequately seeking (medical) care."[149]

5.6.2 Infant feeding

All families would wish to avoid mother-to-child transmission of HIV. In the developed world it is technically possible to virtually eliminate MTCT during pregnancy and at the time of delivery with a combination of drugs for the HIV-infected pregnant woman and the newborn, and post-partum by not breastfeeding the infant. A number of antiretroviral treatment regimens are effective in reducing MTCT. Each regimen has advantages and disadvantages with respect to efficacy, potential toxicity, concerns for future treatment options, and the practicality and feasibility of implementation. Clinical and field trials have demonstrated the feasibility of introducing a short-course regimen of zidovudine, an antiretroviral drug, to achieve a sharp reduction in MTCT in developing world settings—albeit with numerous constraints in the implementation of such a strategy under the field conditions existing in the rural areas of developing countries.[150] Whatever treatment regimen is used, transmission of HIV through breastfeeding remains a concern.[151] Given the option, virtually all HIV-positive pregnant women in the developed world choose a combination of drug therapy and breast-milk substitutes for infant feeding. Policy makers and women in the developing world face a much more difficult choice. In addition to the antenatal and intrapartum occurrence of MTCT, from 14 per cent to over 30 per cent of uninfected infants born to HIV-infected mothers will become HIV-positive as a consequence of breastfeeding. A longer period of breastfeeding is associated with an increased risk of MTCT.[152] Drawing on their extensive international experience, WHO and other organizations in the United Nations system have provided guidelines that advise the following:

> "*Women receiving [antiretroviral] treatment, that is, HIV-infected women, should avoid all breastfeeding when replacement feeding is acceptable, feasible, affordable, sustainable and safe. Otherwise, exclusive breastfeeding is recommended during the first months of life.*" [153, 154]

In the developed world, where safe, nutritious and affordable alternatives to breastfeeding are available, breast-milk substitutes are the preferred and recommended source of nutrition for infants born to HIV-infected mothers. In developing countries, antenatal care is limited, testing programmes are virtually non-existent, effective interventions remain unimplemented, and preventing post-natal transmission of the virus through breast milk while maintaining adequate infant nutrition is a major dilemma.[155] Under controlled clinical trial conditions it has been possible to demonstrate how MTCT can be significantly reduced through the use of breast-milk substitutes in Kenya, with no significant differences in morbidity and mortality rates between infants given breast milk and those relying on substitutes.[156, 157] At the same time, modelling based on available studies suggests that infant survival rates would be higher if breastfeeding HIV-infected mothers waited until their infants reached the age of six months before shifting to breast-milk replacement options.[158] Far more investment in training, health education, HIV/AIDS destigmatization, infrastructure development, and social support is required if both exclusive breastfeeding and the use of "acceptable, feasible, affordable, sustainable and safe" breast-milk substitutes are to become viable options for most of the developing world. Studies indicate that the patterns of exclusive breastfeeding in the developing world, the HIV stigma attached to non-breastfeeding women in many settings, and low levels of adherence to recommended infant feeding strategies are all common obstacles to the implementation of best-practice policy options.[159, 160, 161, 162] The results of a study

conducted in areas of Uganda indicated that even when breast-milk substitutes were provided free and with clear instructions to ensure their safety, the majority of HIV-infected women still chose to breastfeed their babies because not breastfeeding represented an acknowledgement of their own seropositivity.[107] Another study revealed that in areas of Thailand the vast majority of women with HIV were either feeding or intended to feed their infants formula; however, a substantial majority of antenatal women whose HIV status was unknown planned to breastfeed. Virtually all women, regardless of their HIV status, consider breastfeeding to be more advantageous than formula feeding. However, once HIV-infected women are informed of the risk of transmission through breastfeeding, they may or may not decide to follow the Government's recommendation to formula feed.[163] It is interesting to note that in some resource-poor situations in several African countries, whether as part of clinical trials or in the context of efforts to implement infant feeding policy guidelines, only a minority of women adhered to a regimen of either exclusive breastfeeding or the exclusive use of breast-milk substitutes.[159, 160, 161]

The issue of breastfeeding by HIV-positive mothers takes on another dimension with a 2001 report from Kenya indicating that seropositive women who breastfeed may be at a higher risk of dying from AIDS than are those who give their infants breast-milk substitutes.[8] It is hypothesized that the high energy demands of breastfeeding in HIV-infected mothers may accelerate the progression of the disease, leading to an earlier death. While secondary analysis has not confirmed this observation, the issue has become a priority for health authorities.* [164]

5.7 Illness and death

In both developed and developing countries, family members providing care at home for their loved ones with HIV/AIDS require interventions designed to furnish direct and effective support.[88, 113] The nature and focus of these interventions should derive from a comprehensive analysis of the situation on the ground. A study of the factors associated with survival among a group of over 300 parents living with HIV in New York noted that those who reported having more children, seeking social support as a coping strategy, and being sexually active at baseline survived longer. These counter-intuitive findings raise a number of questions regarding changes in roles and responsibilities in the survival of parents with HIV.[165]

In the developing world it is now the elders in families affected by HIV/AIDS who are surviving the ravages of endemic and epidemic disease. Their major concerns include the physical loss of one or more family members, financial problems, and coping with orphans. The pain of physical loss is acute, and the implications far-reaching, because most of those dead are their beloved children and grandchildren, whom they expected to become their heirs and to continue their family or clan line. Without these kinship links the elders feel that their lives are empty. Losing members of the immediate family leaves many of these survivors destitute, isolated, and feeling much older than their years.[78]

The children of parents with catastrophic illnesses have been referred to as the "forgotten grievers". The desire of infected parents to protect their children, combined with their own shock and grief, often diverts their attention away from the needs of their healthy children. Adolescent and adult offspring in such situations have significantly higher depression scores than those of younger children, highlighting a developmental component in the severity of the impact of a parent's illness.[166] With most disabling, chronic or life-threatening conditions only one family member is at risk, but with HIV/AIDS a number of family members may be infected, further aggravating the situation for healthy children in the affected families.[88]

* By the end of 2004, no additional studies on this issue had been reported.

Covering the costs

Even in countries in which the majority of the population lack access to hospital care, a significant proportion of those who die from AIDS or AIDS-related illnesses do so after being hospitalized, adding heavy medical costs to the burden of funeral expenses.[115, 167] Minimum expected standards for funeral ceremonies have evolved in each culture. In the Democratic Republic of the Congo, a casket, a clean sheet, and transportation for the casket and guests to the ceremony are necessary to fulfil the minimum requirements. The average cost of a funeral and wake in Kinshasa is around US$ 320, which is equivalent to eleven months' salary. The cost of a single hospitalization of a child with AIDS is equal to three months of the father's salary, and the child's demise requires another eleven months' worth of earnings. Thus, for each child who succumbs to AIDS, the equivalent of well over a year's salary is the minimum amount that must be paid by the family, the employer or the State.[167]

In the mid-1980s, according to one report,[168] funerals in South Africa began to evolve from modest traditional burials in simple coffins or animal skins to events of defiance and personal political statements. Funerals start at around US$ 200 and can exceed US$ 700 for the more lavish ceremonies, which often include foreign cars, grave-side tents, sound systems and air-conditioned buses for transporting mourners between the grave site and the funeral feast. Most South African blacks have an annual disposable income of less than US$ 925. However, they splurge on funerals, borrowing money when necessary or taking part in burial societies, quasi-insurance plans to which some South Africans contribute up to half of their earnings. Now, with the mounting AIDS death toll, many of those funeral societies and other insurance plans are placing restrictions on their policies and membership, lengthening the time before new members can receive benefits, thereby excluding people in the later stages of AIDS or simply refusing to pay out.

At times, two or three members of the same family fall ill and die over a relatively short period. One member of the family is laid to rest, and a few months later the family has another member to bury; however, the family cannot afford to spend the same amount on the second funeral. In such situations, the financial strain may reach a critical level because AIDS largely affects those in the most economically active age group.[168] Rising rates of death from HIV/AIDS in South Africa have led to the creation of a makeshift funeral industry. "Many 'fly-by-night undertakers', who are unlicensed and operate out of storefronts, compete to make funeral arrangements and leave bodies to decompose while they search for the cheapest means of disposal, creating a health hazard and raising costs to the Government."[169] Because of the stigma surrounding HIV/AIDS, many affected families do not claim the bodies of those who have died, leaving the Government to dispose of them at a cost of US$ 150 each. The Government has rejected the idea of cremating the bodies because African tradition dictates that a person cannot enter the spirit world if his or her body is not buried intact.[169]

CHAPTER 6
FAMILY LIVING ARRANGEMENTS OF CHILDREN: ORPHANS AND FOSTER CARE

Children orphaned by AIDS have become a signature feature of the HIV/AIDS epidemic. In the industrialized world the emotional appeal of orphans draws a wide constituency of advocacy for international solidarity and action. The immediate concern for these vulnerable children, currently and justifiably attracting policy and programme attention,[44, 45] is ultimately linked to the broader consequences of the epidemic for the family. To gain added insight into the role of the family in the acquisition and handling of the disease, and particularly in identifying causes, consequences and various cofactors, it is important to examine HIV/AIDS in the wider context of family living arrangements. Living arrangements constitute an important factor in the accumulation and expenditure of family capital. They identify the individual(s) providing resources for the members of a household, one or more of which may have HIV/AIDS, and are also indicative of the quality of care children are receiving. For the past decade the DHS, and more recently the MICS, have included a module on the living arrangements of children that indicates whether the parents are alive and with whom the children reside.

The nine living arrangement categories specified in the surveys* collectively represent a point of departure for a more extensive analysis of the impact of the HIV/AIDS epidemics on families. It should be noted, however, that these categories reflect the living arrangements of all children in the DHS and MICS samples and therefore provide only an approximation, rather than a precise estimate, of family household arrangements since some parents may be caring for both their own children and those of other relatives. The numbers of families in the relevant categories will be overestimated to the extent that certain households include all or some of the parents' biological children as well as one or more foster children (the offspring of a relative). The analysis undertaken in this chapter reflects the family household living arrangements of children in 34 sub-Saharan African countries.† Figure IX shows the overall range and mean for each of the nine categories, though it does not portray the wide variation in the prevalence of each of the household arrangements among individual countries. In contrast to the estimates of families affected by HIV/AIDS in previous chapters, the statistical analysis of living arrangements in this chapter does not reflect the family structure per se, but rather the country patterns of family household living arrangements of children. To strengthen the focus of the present analysis where possible and appropriate, the indicator "annual rate at which families are newly affected by HIV/AIDS" (also referred to as the incidence rate of families affected by HIV/AIDS) has been used, based on the most recent 2001 and 2003 country-specific estimates and data from UNAIDS. This indicator is in part made up of families affected by the death of one or both parents from AIDS, which obviously affects the living arrangements of children. In the first subsection, below, the analysis has been limited to living arrangements in which the mother and father are alive, and the children may be living with neither, one or both parents. With these caveats, the interpretation of any significant statistical associations should translate into reasonable hypotheses warranting follow-up and further analysis rather than implying any proven association.

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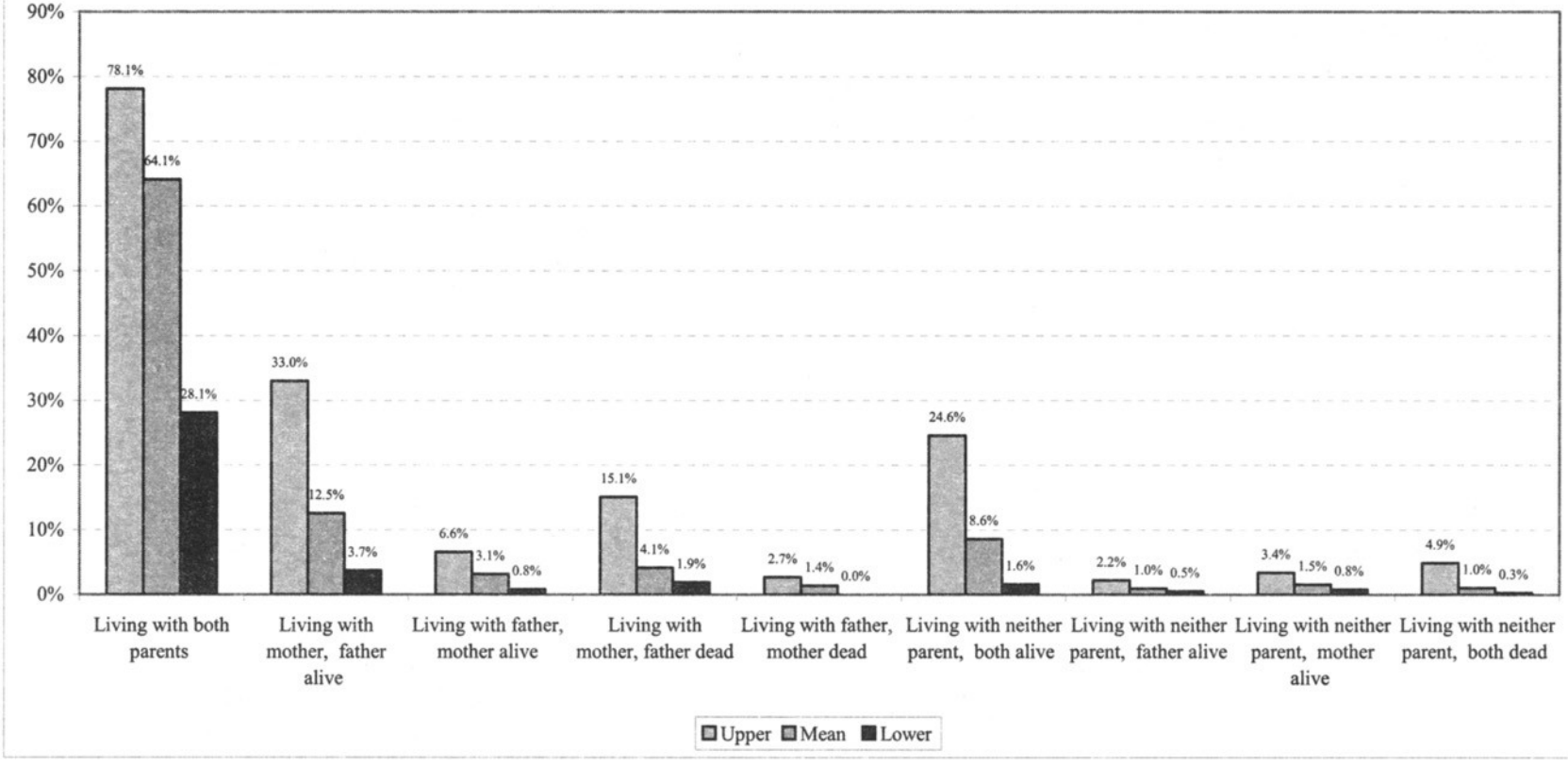
* The categories specify the residential arrangements for children as follows: (1) living with both parents; (2) living with the mother, though the father is alive; (3) living with the mother, the father having died; (4) living with the father, though the mother is alive; (5) living with the father, the mother having died; (6) not living with either parent, though both are alive; (7) not living with either parent, the mother having died; (8) not living with either parent, the father having died; and (9) not living with either of the parents, both having died.

† See annex II for a list of data sources.

Figure IX. Upper and lower ranges and mean for the family household living arrangements of children in 34 sub-Saharan African countries, circa 2001 (percentage)



Sources: Data for the models and analysis were obtained from the 34 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003 as noted in Annex II of the present publication.

Each of the categories and combinations of living arrangements offers potential insight into the impact of HIV/AIDS on the family in terms of causality and consequences, and in measuring the degree of association of a factor or factors as yet unidentified. These relationships have been examined through the use of multiple regression analysis in which the prevalence of specific factors and living arrangements is attributed to individual countries. The approach is not as statistically robust as characterizing individual families, but is sufficient for generating reasonable hypotheses for more detailed analyses of the primary data in the course of formulating appropriate policies and programmes.

The most common arrangements are children living with both parents (group 1 of the nine identified in figure IX); children living with their mothers but not their fathers, though the latter are alive (group 2); children in foster care, though both parents are alive (group 6); and children living with their mothers, their fathers having died (group 4). Among the sub-Saharan African countries studied there are wide variations in the prevalence of particular living arrangements, with proportions ranging from 28 to 78 per cent and a mean of 64 per cent for group 1; a range of 4 to 33 per cent and a mean of almost 13 per cent for group 2; a range of 2 to 25 per cent and a mean of 9 per cent for group 6; and a range of 2 to 15 per cent and a mean of 4 per cent for group 4.* Only in Latin America and the Caribbean are similar, albeit less wide, variations found (see annex IV, figure II).

Family living arrangements evolve for many reasons. Events beyond the family's control, such as the death of a parent, may force a shift in the composition of the household, or a family may make a conscious decision to allow one or more of its members to reside elsewhere. An example of the latter is housing children with others in the family network so that they may attend school or serve an apprenticeship in a larger town or city. In other instances, especially in subsistence farming settings, the father may become a short- or long-term rural-to-urban or international economic migrant, remitting his earnings to increase the family's income and/or acquiring entrepreneurial or technical skills. These voluntary arrangements are perceived positively; however, they may place additional stress on the family, owing not only to the member's physical absence but also to the increased risk of that person, and ultimately others in the family, being infected with or affected by HIV/AIDS.

6.1 Families with children in which both parents are alive

In much of the developing world, and particularly in Asia (including Central Asia), at least 80 per cent of children under the age of 15 are living with both parents. In Latin America and the Caribbean the range between countries is relatively wide. In the Dominican Republic and Haiti, for example, around 50 per cent of children live with both of their parents, while in Nicaragua and Colombia the proportion is about 60 per cent, and in most other countries the rate is around 75 per cent (see annex IV, figure II). Three quarters of the children live with both parents in only 3 of the 34 sub-Saharan African countries under review.

In virtually all countries the education of children is a major factor in the allocation of family resources and in economic, employment and family living arrangement decisions. Factors influencing whether and where children obtain schooling include population density, the existence of a school system and infrastructure, family income or economic status, and the social position of women (including the level of women's education). It is hypothesized that the level of children's schooling is correlated with the proportions of absentee fathers and of foster children living in family households, particularly when both parents are alive, based on observations for many sub-Saharan African countries regarding the lack of an extensive school infrastructure in rural areas, the strength of family networks, and the family's need for

* In Rwanda, the proportions of children whose living arrangements reflect the death of the father or of both parents are relatively high, at 15.6 and 5.1 per cent respectively; this situation is believed to be largely attributable to the genocide.

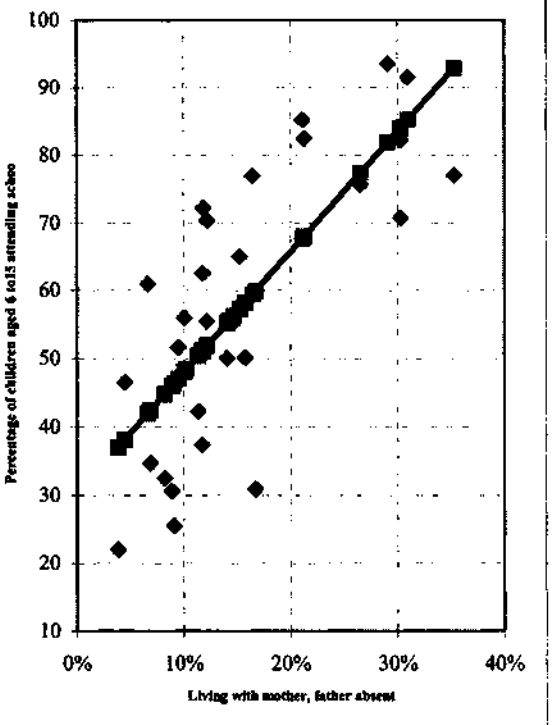
supplemental income, especially among subsistence farmers, to cover school fees and the cost of school uniforms and books

These assumptions are validated in an analysis of sub-Saharan African countries for which data on child schooling and family living arrangements are available. First, among the 32 countries examined, there is a strong correlation between the prevalence of school non-attendance among children 6 to 15 years of age and the lack of schooling among women, accounting for more than two thirds of the variation in the education of children (see annex III, table 2). Second, about 30 per cent of the variance in the prevalence of children attending school in these countries is associated with the increasing percentage of children in foster care whose parents are alive (see annex III, table 3), and 55 per cent of the variation in school attendance is associated with living arrangements in which children reside with their mothers but have fathers living elsewhere(see figure X and annex III, table 4).

In settings characterized primarily by rural dispersed populations, foster care and the economic migration of fathers appear to be part of the family's strategy for educating children. The prevalence of foster care and the percentage of children attending school are particularly high in southern Africa, where the proportion of families with absentee fathers is also high. The father's absence may be linked to economic migration—and the higher attendant risk of contracting HIV/AIDS.

There is a strong correlation between the rate at which families are newly affected by HIV/AIDS and children's living arrangements in which both parents are alive but either the father is absent* or the children are living in foster family households. Between 31 and 41 per cent of the variation in the annual incidence rate of affected families is associated with these living arrangements among children. The combined

Figure X. Correlation between school attenance and the proportion of children who reside with the mother while the father is alive but absent, 32 sub-Saharan African countries, circa 2001



Source: Data for the models and analysis were obtained from the 32 national Demographic and Health Surveys and UNICEF- sponsored Multiple Indicator Cluster Surveys from 1995 through 2003 as noted in Annex II to the present publication.

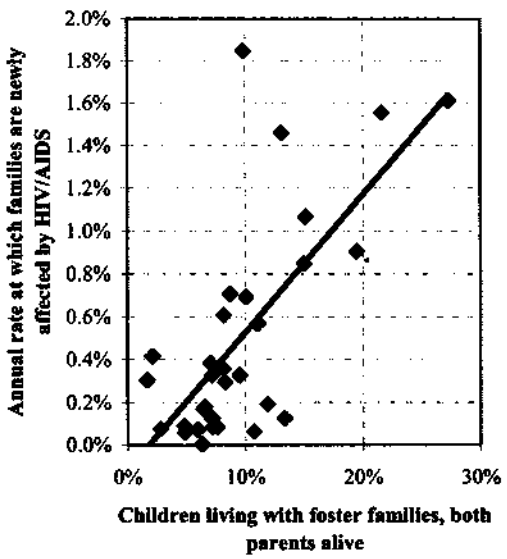
effect of women's education (added to the regression model) and the proportion of non-orphaned children living in foster family households increases the statistical significance of the correlation, with the two factors accounting for 45 per cent of the variation in the percentage of families newly affected by HIV/AIDS (see figures XI and XII and annex III, table 5).

This section has focused primarily on the link between HIV/AIDS and living arrangements in which both parents are alive but may or may not be present in the family household in which their children reside. A consistent statistically significant correlation has

* Divorce, the rates for which range from 1 to 5 per cent, is not statistically correlated with absentee father prevalence rates in the DHS sample of sub-Saharan African countries.

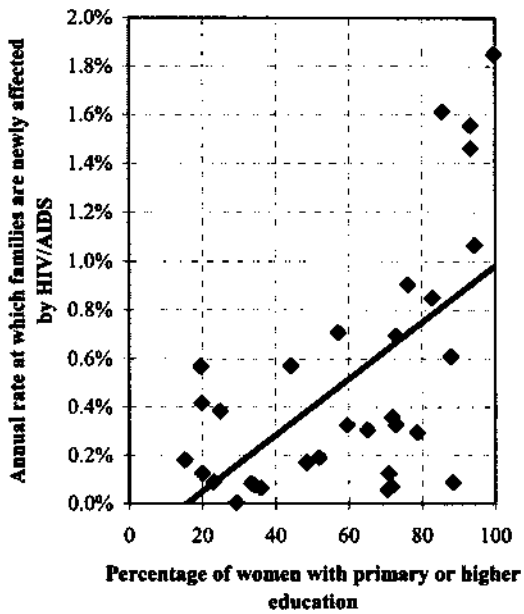
been demonstrated through comparison of the patterns of both child schooling and the two HIV/AIDS indicators (adult HIV prevalence and annual rates at which families are newly affected by HIV/AIDS) with the prevalence of those living arrangements characterized by child foster care and by a present mother but absentee father. A reasonable hypothesis is that it is the behaviours absentee fathers engage in while away from the family, rather than their absence per se, that is responsible for the direct correlation between HIV/AIDS and such living arrangements.

Figure XI. Correlation between the incidence rate of HIV/AIDS-affected families and living arrangements of children in foster families though both parents are alive, 32 sub-Saharan African countries, circa 1998-2003



Sources: Data for the models and analysis were obtained from the 32 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2002 Revision* (CD-ROM) (New York, 2003) (United Nations publication Sales No. E.03.XIII.8).

Figure XII. Correlation between the annual rate at which families are newly affected by HIV/AIDS and the educational status of women, 32 sub-Saharan African countries, circa 1998-2003



Sources: Data for the models and analysis were obtained from the 32 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2002 Revision* (CD-ROM) (New York, 2003) (United Nations publication Sales No. E.03.XIII.8).

Separate analyses showed no association between HIV/AIDS indicators and living arrangements when children were with the father, although the mother was alive, but absent. However, when paternally orphaned children were not living with the mother a significant correlation with the incidence newly HIV/AIDS affected families, accounting for 37 per cent of the variation in the latter. (p <0.0002) It was not possible to determine whether or not this correlation was due to a possible

contribution of paternal AIDS-related deaths to the regression analysis.

The foregoing analyses constitute a first step in researching the dynamic link between the HIV/AIDS indicators and the family living arrangements of children. As demonstrated by the analyses of families with both parents alive, the findings regarding absentee parents (particularly fathers) and the process of foster care are significant enough to warrant further in-depth study and analysis based on the attributes of individual family households. Such analysis is possible with the existing primary data available in the DHS and MICS, but direct household analysis of living arrangements and HIV/AIDS would only be possible with the national DHS databases for those three countries* in which HIV testing was offered to and accepted by a subsample of adults linked to the larger sample of households.

6.2 Orphaned families†

Global estimates indicate that by the end of 2003, 15 million surviving children under the age of 18 had lost one or both parents to AIDS; 12.3 million of them were living in sub-Saharan Africa.[45] By 2010, the latter figure is expected to jump to 18.4 million.[45] Of the 43.4 million orphans in sub-Saharan Africa at the end of 2003, 28 per cent had been orphaned as a result of AIDS; by the end of 2010, these figures are projected to rise to 36.8 per cent of an estimated 50 million orphans.[45] Between 1990 and 2003 the proportion of orphaned children declined from 8.8 to 7.3 per cent of the population in Asia and from 7.1 to 6.2 per cent in Latin America and the Caribbean. During the same period, orphan prevalence in sub-Saharan Africa increased from 10.9 to 12.3 per cent, with the AIDS-related share rising from 1.9 to 28.3 per cent.[45] An analysis of DHS and MICS data relating to children under the age of 15 from 28 non-African developing countries indicates that the prevalence of orphans is lower than 6 per cent in all countries except Cambodia (7 per cent) and Haiti (10 per cent). The most recent corresponding figures for 36 sub-Saharan African countries indicate that orphan prevalence ranges from 5.2 to 5.9 per cent in six countries and from 6 to 19.1 per cent in 29 countries,[44, 45] and in one country, Rwanda, nearly 5 per cent of the children have lost both parents and another 22 per cent have lost either a father or mother,[170] largely as a result of genocide.

The death of a father and the death of a mother have very different implications for the surviving children and for the family as a whole. In the developing world, the share of paternal orphans is generally higher than that of maternal orphans; in the 33 sub-Saharan African countries for which data are available, single-parent paternal and maternal orphan prevalence rates not attributable to AIDS range from 2.8 to 9.5 per cent and from 2.1 to 8.4 per cent respectively (see figure XIII). The higher paternal orphan rates are generally attributable to differences in the age of marriage and concomitant mortality risks, and to the higher prevalence of accidents and of occupational and other external causes of death among men. Violence, in particular extended armed conflict, is a significant contributor to male mortality in many areas; the four countries with the highest proportions of paternal orphans are among those that have endured prolonged and often brutal armed conflicts.

Maternal orphan rates are closer to paternal orphan rates in areas characterized by high fertility, in which women experience early, late and inadequately spaced pregnancies and bear

* Ghana, Kenya and Mali.

† The most recent UNAIDS data have been used by UNAIDS, UNICEF and USAID to revise the analysis of children and youth orphaned by AIDS. These data cover all children under the age of 18, as contrasted with earlier data from UNAIDS, as well as DHS and MICS survey data, which specify a cut-off of 15 years. Unfortunately, the methodology used for classifying children and the presentation format are incompatible with the analysis on living arrangements. Therefore, in this section, the results of the updated publication will be presented as descriptive data; they will not be used to undertake any further secondary analysis. Secondary analysis will be based on the DHS and MICS data on living arrangements.

multiple children. The risks are compounded when women have difficulty obtaining access to adequately staffed and equipped essential obstetric services and facilities. These measurable factors are summarized in the indicator "lifetime risk of dying during pregnancy, delivery or the post-partum period" (see annex IV, figure III). Among the 33 sub-Saharan African countries for which suitable data are available, this indicator is correlated with non-AIDS-related maternal orphan prevalence, accounting for 16 per cent of the variation in the latter (see annex III, table 6).

The children orphaned by AIDS in sub-Saharan Africa constitute as little as 4 to 5 per cent of all orphans in Gambia, Niger and Senegal and as much as 77 to 78 per cent in Botswana and Zimbabwe.[45] The wide range reflects not only the levels of HIV infection in the countries under review, but also the variable patterns of other infectious diseases (such as malaria), nutritional deficiencies, and the accessibility and adequacy of health services for the treatment of adult diseases. The health infrastructure in many southern African countries has been adversely affected by the recent AIDS epidemic; previously, it was considered reasonably well developed in comparison with that in some other regions, and malaria was not a problem or was controlled.

The pattern of maternal and paternal deaths from AIDS is opposite that of maternal and paternal deaths from other causes. In situations in which parental AIDS is a factor, rates for maternal orphans are higher than those for paternal orphans in all settings except those in which less than 1 per cent of the orphan prevalence is linked to AIDS. AIDS-related maternal orphan rates range from 0.2 to 13.4 per cent of all children, while the corresponding paternal orphan rates range from 0.2 to 9.1 per cent (see figure XIV).

6.2.1 Living arrangements following the death of one or both parents

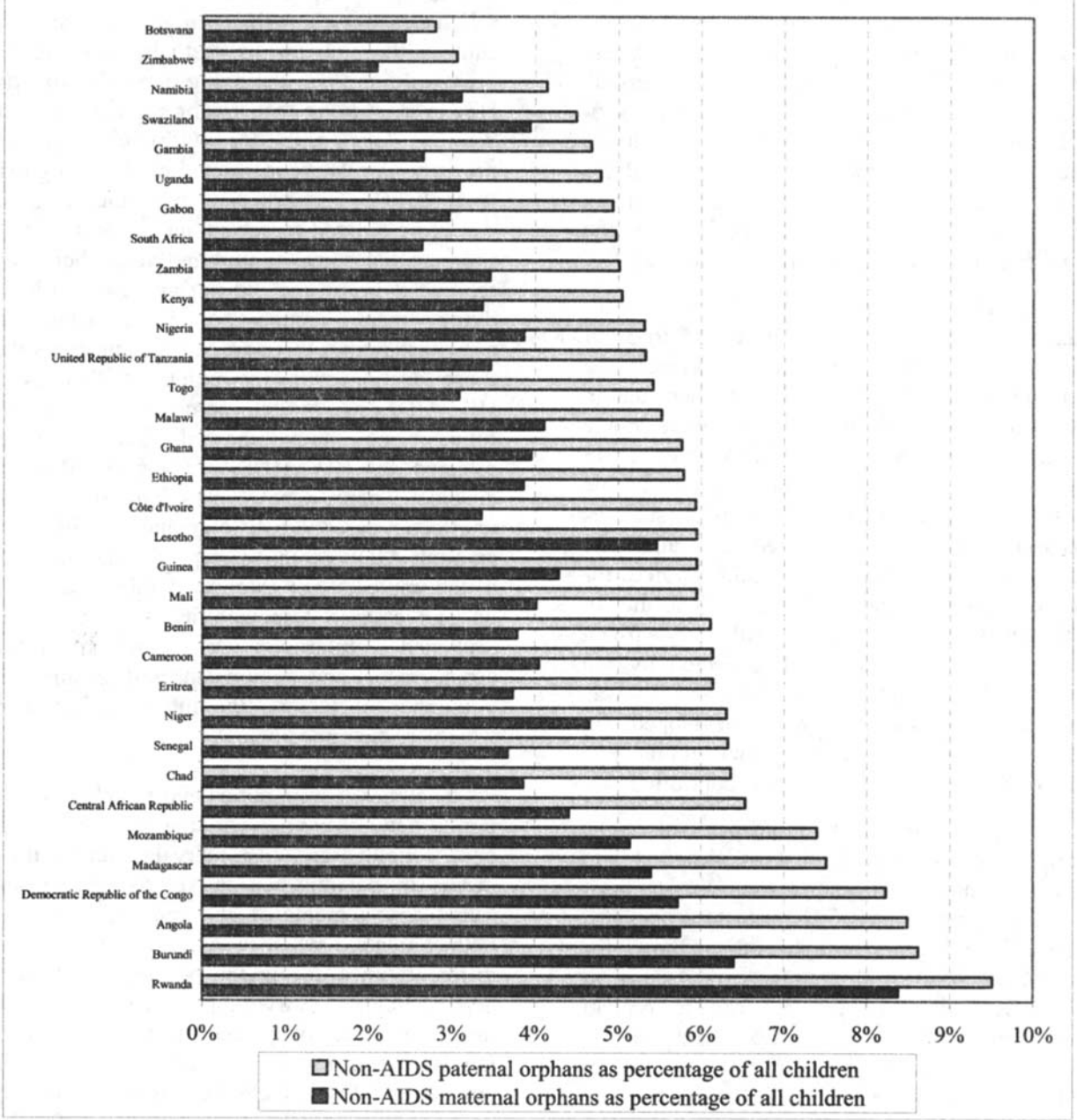
Among the needs of families affected by HIV/AIDS are succession and permanency planning. Various studies have shown that very few parents living with HIV/AIDS make plans or provisions for the future of their children, though they all express anxiety about the issue.[171] In Zimbabwe succession planning with a dying person is considered improper, as the relative raising the subject might be accused of causing the sickness or death by showing too great an interest in the dying person's property. However, a dying man might stipulate what he wanted done with his wife, children and property. A relative instructed by the dying man to look after his property and other interests would be obliged to accept such a commission, for fear that some misfortune would befall the relative if he or she did not agree to fulfil the dying man's request.[172] Such tendencies notwithstanding, there are some indications that those dealing with the unique challenges of HIV/AIDS are giving some thought to the future; one study showed that caregivers affected by HIV/AIDS were more likely to consider permanency planning than were unaffected caregivers.[173] Nonetheless, following an adult AIDS death it is typically the members of the immediate or extended family that decide on and assume responsibility for the care of orphaned children, with specific living arrangements and circumstances determined by a number of factors, the most significant of which are examined below.

Societies, communities and members of the family network invoke variable combinations of civil, religious and customary law and cultural norms in deciding on the custody, care and living arrangements of children who have lost both parents,* whether simultaneously or at different times during the period of childhood dependency. Surviving children are institutionalized or placed in family or non-family foster care, or end up among the population of street children, with whom they establish mutually supportive "family" structures. Until the 1990s, at least in Africa, members of the extended family took in most children whose parents had died; in the era of AIDS this practice has become less common in many areas.[174]

* Referred to as "double orphans".

Figure XIII. Comparison of the prevalence of maternal and paternal orphans from parental deaths not attributable to AIDS, 33 sub-Saharan African countries, circa 1998-2001

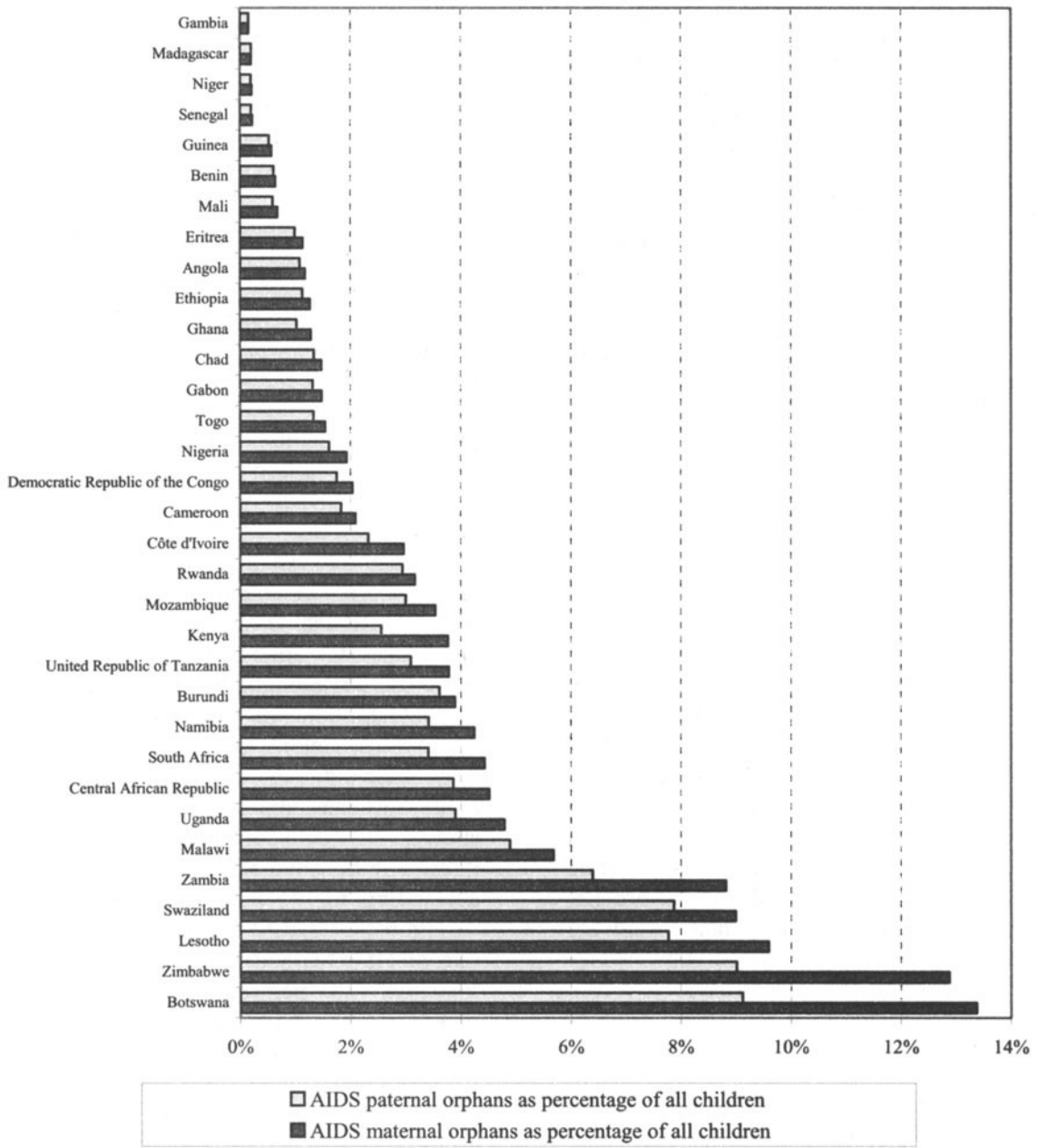
(Percentage)



Source: Joint United Nations Programme on HIV/AIDS, United Nations Children's Fund and United States Agency for International Development, *Children on the Brink 2004: A Joint Report of New Orphan Estimates and a Framework for Action* (Washington, D.C., USAID, July 2004), available at www.unaids.org, www.unicef.org, or www.usaid.gov.

Figure XIV. Comparison of the prevalence of maternal and paternal orphans from parental deaths attributable to AIDS, 33 sub-Saharan African countries, circa 1998-2001

(Percentage)



Source: Joint United Nations Programme on HIV/AIDS, United Nations Children's Fund and United States Agency for International Development, *Children on the Brink 2004: A Joint Report of New Orphan Estimates and a Framework for Action* (Washington, D.C., USAID, July 2004), available at www.unaids.org, www.unicef.org, or www.usaid.gov.

Before AIDS reached epidemic proportions, the foster care of both orphaned and non-orphaned children was undertaken within a specific cultural context in which the structure and obligations of family networks, norms for childcare (including arrangements for educating the young), and cultural and legal responses to the death of one or both parents were clearly defined and respected. In African families it was "common to see a child entrusted to other members of the family ... for strictly educational reasons (the child would be closer to the school and better attended to by an uncle), ... for socio-economic reasons (the child would be employed as a "boy" or servant by the family lodging him ...) or to conform to cultural norms (ritual residence with a grandparent, care of the child by a maternal uncle, etc.)".[175] In Malawi, a preliminary investigation indicated that "cultural factors influenced various aspects of family foster care, ranging from the caregivers' decision to foster children to the caregivers' determination not to disclose to the children that they were fostered. Social and economic factors also played a role."[176]

The diversity and percentages of orphans in the various household residential arrangements have increased with the spread of the epidemic and the consequent rise in the numbers of orphans. Throughout Africa, it would appear that most orphans have been taken in by existing families.[177] AIDS has been responsible for an enormous increase in family foster care. While most children of HIV-infected parents are not infected, both the children and their caregivers are affected by the disease.

The epidemics have altered traditional practices governing the designation of responsibility for the care of orphans. In several countries in Africa, there was a time when the paternal extended family would customarily care for the children upon the death of one or both parents. Now, as an adaptation of community coping, maternal relatives are increasingly among the caregivers for orphans.[171, 172] Studies from Uganda indicate that decisions about who is to care for orphaned children are made by clan members (around 30 per cent, and more commonly in paternal orphan situations), parents (27 per cent) and grandparents (15 per cent). Around 40 per cent of orphans are cared for by surviving parents, 25 per cent by grandparents, and 20 per cent by other relatives. Maternal orphans tend to be cared for by grandparents rather than by the surviving father.[112] Assistance from friends or NGOs is negligible.

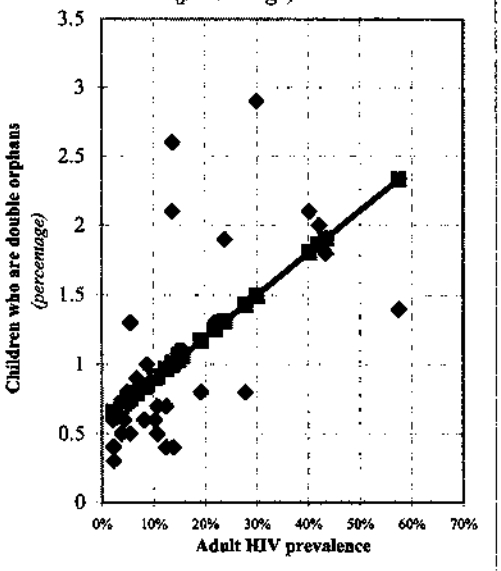
In most regions of the developing world the proportion of children who have lost both parents (and are therefore typically in foster care) is quite low, ranging from one to two children per thousand in Central Asia, Europe, North Africa and Western Asia. The rates tend to be slightly higher in Latin America and the Caribbean (0.2 to 0.8 per cent) and in South and South-East Asia (0.2 to 0.6 per cent). While double orphan situations are still relatively uncommon in sub-Saharan Africa, overall prevalence is at least five times higher than in the majority of developed and developing countries elsewhere in the world. Between 0.2 and 5.1 per cent of the children in sub-Saharan Africa can be classified as double orphans. The rate of 5.1 per cent reflects the consequences of the genocide in Rwanda (unusual circumstances); among the other 33 countries for which data are available, an average of 1.1 per cent of children are double orphans [45, 170] (see figure IX). Among the various factors seen as directly or indirectly affecting the prevalence of double orphans, only the HIV/AIDS indicators show a significant correlation, the double orphan rates, with the adult HIV prevalence rate in 2003 accounting for 35 per cent (p <0.001) of the variation (see figure XV), while the incidence rate of HIV/AIDS affected families accounting for only 23 per cent (p <0.005) of the variation.in the double orphan rates. Neither the lifetime risk of pregnancy-related death nor women's educational attainment is significantly associated with the prevalence of double orphans.

Families make living arrangement decisions based on past experiences, cultural norms, perceived advantages with regard to their well-being, and the need to ensure the security and protection of family members. A suitable indicator of family security is not available for

regression analysis; however, from an overview of the living arrangement indicators "families with orphans" and "foster families with children whose parents are both alive", it can be

Figure XV. Correlation between adult HIV prevalence and the proportion of double orphans in 32 sub-Saharan African countries,* 2003

(percentage)



Source: UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and Joint United Nations Programme on HIV/AIDS, United Nations Children's Fund and United States Agency for International Development, *Children on the Brink 2004: A Joint Report of New Orphan Estimates and a Framework for Action* (Washington, D.C., USAID, July 2004), available at www.unaids.org, www.unicef.org, or www.usaid.gov.

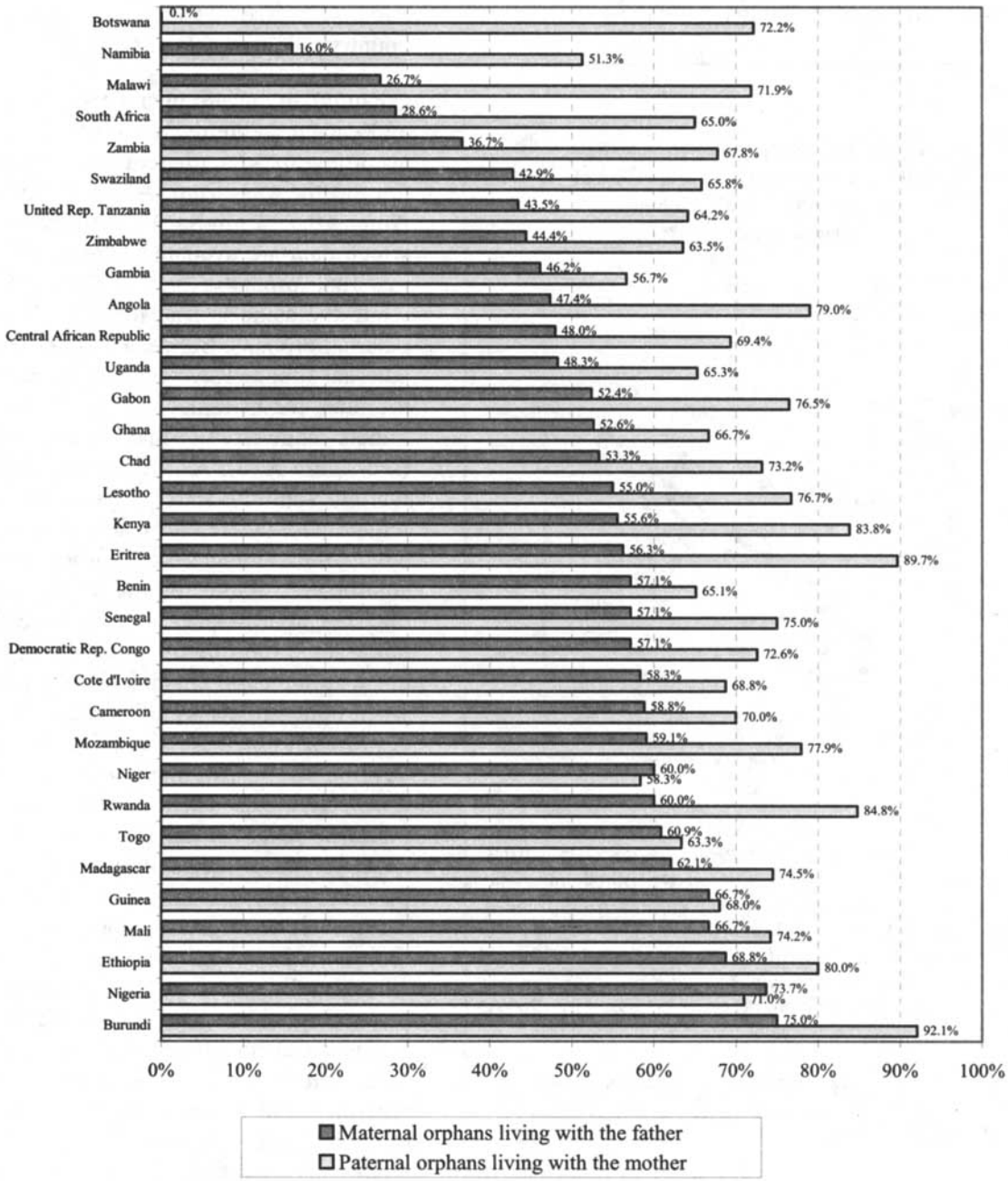
* Rwanda is not included owing to the unusually high proportion of double orphans attributed to genocide, while Uganda was not included because of the impact of its AIDS control programme.

hypothesized that either the opportunity or the decision to place children in foster care, usually for the purpose of facilitating their education, is lacking in countries that have endured prolonged military conflict and/or genocide. This hypothesis is based on the observation that the four sub-Saharan African countries* with the widest gaps between high orphan prevalence and low foster-care rates for children with both parents alive have experienced major countrywide internal conflicts.

Family living arrangements, patterns of care, and even children's survival rates vary according to which parent has died and whether the death was from AIDS or other causes. Among the 33 sub-Saharan African countries for which data are available, around 49 per cent of maternal orphans live in family foster care, while the same is true for only 29 per cent of paternal orphans. Between 51 and 92 per cent of paternal orphans live with their mothers, while the rates for maternal orphans living with their fathers range from virtually none to 75 per cent (see figure XVI). As the figures suggest, child-rearing and childcare responsibilities tend to remain with the mother when the father dies, but when the mother dies these functions are significantly more likely to be assumed by others. Circumstances in which the father does not assume the role of primary caregiver and is not with the child characterize the pattern found when both parents are alive but only the mother is present to care for the child. In much of the developing world the death of a mother, irrespective the cause, greatly increases the mortality risks for her surviving children.[178, 179] In long-term studies from the Gambia, the positive effect of maternal survival on child survival is also found when children have a living maternal grandmother or elder sisters, whereas the presence of a living father, a paternal grandmother, a grandfather or elder brothers has no effect on child survival.[180] A long-term study from Uganda indicates that regardless of children's HIV status, child mortality risks increase in association with, inter- alia, terminal illness or death of the mother's HIV seropositivity, or the mother's absence.[181]

* Angola, Burundi, Eritrea and Rwanda.

Figure XVI. Percentages of orphans living with the surviving parent, 33 sub-Saharan African countries, circa 1998-2001



Sources: Data for the analysis were obtained from the 33 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2001.

Family decisions regarding the care and living arrangements of both orphaned and non-orphaned children derive from the particular circumstances surrounding each situation. For example, while the prevalence of maternal orphans in foster care is somewhat associated with the overall percentage of children orphaned, it is women's educational level alone that is most strongly associated with the percentage of maternal orphans in foster care, accounting for 24 per cent of the variation in the latter (see annex III, tables 7 and 8). The strong association of women's education with children's school attendance lends additional weight to the proposition that families' educational objectives are an important motivation for foster family living arrangements. Furthermore, the percentage of maternal orphans living with their fathers is inversely correlated with the percentage of children who reside with their mothers but have living, non-resident fathers (see annex III, table 9). As the proportion of maternal orphans living with their fathers declines, the total proportion of children receiving a primary education increases (see annex III, table 10). The significance of these various factors becomes more apparent when they are examined as independent variables in association with the annual rates at which families are newly affected by HIV/AIDS. In a multivariate analysis only the effects of women's education and those living arrangements in which both parents are alive but absent (with the children in foster care) are statistically significant, accounting for 44 per cent of the variation in the indicator "families newly affected by HIV/AIDS" (see annex III, table 5), whereas children's education and the other living arrangements in which both parents are alive but one or the other is absent are not significant.

In contrast to the situation characterizing maternal orphans, there are no statistically significant relationships, alone or in combination, between the proportion of paternal orphans in foster care and school attendance, other living arrangements of children, the rate at which families are newly affected by HIV/AIDS, or adult HIV prevalence. Widowed mothers and their children are increasingly bearing the brunt of the epidemic, with many suffering rapid and substantial losses of family capital. These observations clearly warrant further research, and if their validity is confirmed, an explanation should be sought based on the underlying social, cultural and family decision-making processes. Do mothers tend to remain the caregivers of paternal orphans by choice or out of economic necessity? Does a widowed mother require the economic contributions of her children to survive? Does the lack of a father's income make it impossible for the family to pay school fees? Is the mother's family network unable or unwilling to bear any of the burdens or costs of caring for the surviving children? These are among the essential questions that must be answered in the process of fashioning a family policy agenda and programmes in response to the epidemic.

6.2.2 Children orphaned by AIDS and discrimination in education

As the prevalence of orphaned households and the numbers of foster children in surviving households continue to increase, foster families have fewer and fewer resources available to meet each child's needs. While foster children may constitute an additional source of labour, they tend to be unskilled and inefficient in this context and are generally unable to offset the extra burden they place on the families charged with their care. In resource-poor settings foster families may concentrate the limited funds they have available for school fees, books, uniforms and other education expenses on their own (biological) children, with the foster children given lower priority. School attendance thus serves as a direct indicator of the preferential treatment some children receive. It also may serve as a measure of the impact of HIV/AIDS on family capital. A report highlighting the effects of AIDS mortality on children's education in Kampala indicated that 47 per cent of the children of foster parents did not go to school, compared with 10 per cent of the children of non-fostering parents.[182] Since this report was released in 1990, data on school attendance have been systematically collected and reported in the DHS and MICS, albeit in

somewhat different formats. DHS data are reported for children between the ages of 6 and 15, while the age groups in the MICS reports vary from one country to another.

The issue of discrimination, education and HIV/AIDS may be examined at three levels: Is there discrimination against the orphaned child? Are there gender differences in school attendance based on orphan status? Is there discrimination or lack of schooling because a family is affected by HIV/AIDS? The DHS reports for 24 sub-Saharan African countries present data on discrimination in terms of the ratio of orphans to non-orphans in school attendance, which would be equal to one (with an arbitrary ±0.05) in the absence of discrimination or preferential support for schooling. A ratio of 1.0 (±0.05) has been defined in the present context as the absence of discrimination in school attendance.

Discrimination against orphans in education is neither universal nor consistently disadvantageous to girl children among the sub-Saharan African countries under review. There is no evidence of discrimination against paternal orphans of either sex in eight countries,* nor among maternal orphans in four countries† (see figures XVII and XVIII). The magnitude of the disadvantage in education experienced by orphans‡ ranges from about 8 to 16 per cent, depending on the sex of the child and which parent is deceased (see table 3). School attendance ratios indicate a slight, but not statistically significant, disadvantage for orphaned girls, and a significantly reduced disadvantage for paternal orphans (see table 3). While the aggregate data show relatively small differences, the general disadvantage in education for orphaned girls is evident in a number of (though not all) countries clustered in western sub-Saharan Africa. Those countries with little evidence of gender-based differences, or even somewhat of an advantage for orphaned girls, tend to be found in southern and eastern Africa (see figures XVII and XVIII).

Among the factors examined as possible correlates of the variations in orphan to non-orphan school attendance ratios were the different living arrangements of children, the overall percentage of children attending school, maternal and paternal orphan rates, and the HIV/AIDS indicators "adult HIV prevalence" and "the incidence rate of families affected by HIV/AIDS". Only the percentage of children attending school was significantly correlated with the variations in any of the orphan to non-orphan ratios (see annex III, table 11). The higher the percentage of children in school, the less likely there was to be an orphan disadvantage in school attendance. Only among paternally orphaned boys did this relationship not exist, largely because of the relatively low rate of male orphan disadvantage in school attendance.§

6.2.3 An overview of the family foster re situation: challenges and remedial strategies

The relationships between biological and foster children in a family and the health and development of each are issues requiring further consideration. The biological children of foster parents must share food, clothing, rooms, beds, and other items and facilities in their homes with orphans, which may negatively affect their health and welfare. "It is possible these children will grow up resenting the fostered children and perhaps the system of child fosterage. The situation is likely to be worse for the orphans, who may have little right of protest in their foster parents' homes. Although the relatives are still willing to help, it seems the problem of orphans has gone beyond the capacity of

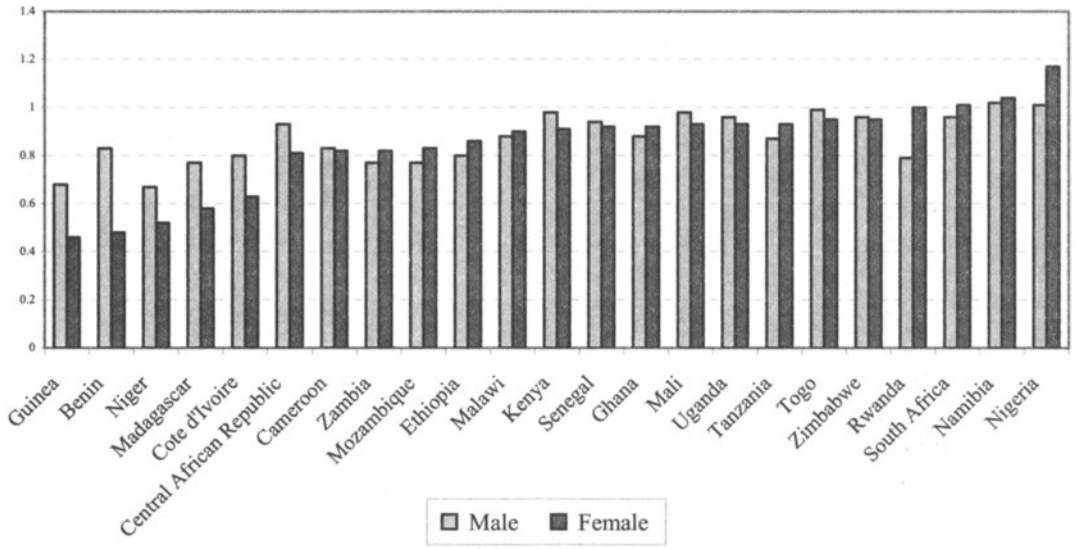
* Mozambique, Namibia, Rwanda, South Africa, Uganda, United Republic of Tanzania, Zambia and Zimbabwe.

† Namibia, South Africa, Togo and Zimbabwe.

‡ Estimated as one minus the ratio of orphans to non-orphans attending school.

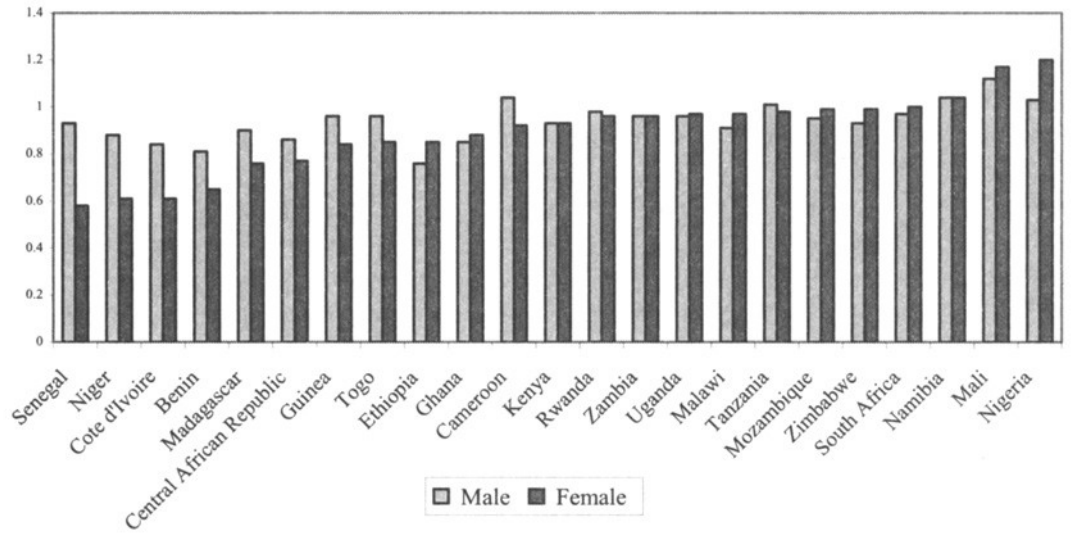
§ Only one of the 23 countries under review exhibited more than a 20 per cent male orphan disadvantage in school attendance.

Figure XVII. Ratios of maternal orphan to non-orphan children attending school, 23 sub-Saharan African countries, 1992-2003



Source: Data for the analysis were obtained from the 23 national Demographic and Health Surveys from 1995 through 2003 as noted in Annex II to the present publication.

Figure XVIII. Ratios of paternal orphan to non-orphan children attending school, 23 sub-Saharan African countries, 1992-2003



Source: Data for the analysis were obtained from the 23 national Demographic and Health Surveys from 1995 through 2003 as noted in Annex II to the present publication.

Table 3. Comparison of the mean ratios of orphans to non-orphans in school attendance based on the sex of the child and which parent is deceased
23 sub-Saharan African countries

	Ratio of male orphans to male non-orphans attending school	Ratio of female orphans to female non-orphans attending school	Statistical significance
Mother dead, father alive (maternal orphans)	0.873	0.842	None
Father dead, mother alive (paternal orphans)	0.938	0.890	None
Statistical significance	*p<0.025*	None	

Source: Data for the models and analysis were obtained from the 23 national Demographic and Health Surveys from 1995 through 2003, available at http://www.measuredhs.com/.

extended families, and outside assistance is urgently needed."[183]

Increasingly, there are indications that the children orphaned by AIDS are not receiving the same level of support as the biological children in kinship- and non-kinship-based foster families. Findings from focus group studies[172] suggest that many orphans are neglected, receive insufficient care, food and other basic necessities, have more health problems, and are generally unhappy; even young children may be put to work, and caregivers may be unwilling or unable to pay school fees. The studies provide examples of orphans who were exploited or physically abused and subsequently ran away from their foster homes. Focus group discussions with community members have indicated that orphans are often stigmatized; these children may experience social isolation once it is widely known in the community that they have lost one or both parents.

Social attitudes notwithstanding, community members have remarked upon how well behaved orphans are. Some have observed that they are quiet, careful children who are likely to be beaten and blamed for family misfortunes. They may be given an excessive amount of work to do in their foster homes and may be treated differently from the members of the caretaker's biological family. Teachers relate that it is possible to identify orphaned children by the differences in their attitudes or behaviour, or by the fact that they are underfed, poorly dressed, or not provided with school fees.[172] According to a UNICEF study on Kenyan children orphaned as a result of AIDS, those taken in by relatives tend to be treated as second-class members of the family, discriminated against in everything from food to schooling, sometimes abused, and often forced to work. While most of those answering the study questionnaires agreed that relatives should care for orphaned children, most family members charged with the care of children orphaned by AIDS admitted in focus group interviews that they would prefer to institutionalize the children. "They've realized that they are not able to cope anymore."[174] In the orphanages being built in response to the crisis, there are some children whose parents died of AIDS or AIDS-related illnesses. Others have been brought in by HIV-positive parents who have assumed that either they or their offspring, or both, will soon die. Some of the children have simply been abandoned. "Fewer and fewer relations are willing to take in orphans."[174]

In one region of Uganda, orphans appear to die earlier and have higher mortality rates than other children. Research shows that they "may be overworked by relatives or other guardians who consciously or unconsciously view them as a burden. Lack of supervision, proper caretaking, and school or vocational activities leads to poor socialization, alienation from guardians and the community, and possible delinquency. Guardians predict reduced

opportunities for orphans, who remain uneducated, untrained, and unemployable."[184]

Among the findings of studies conducted in Uganda is an analysis of focus group discussions with guardians of children orphaned by AIDS. The analysis indicates that many guardians are "too young or too old to properly care for the children's material or psychological needs. Cases of special stress include wives surviving deaths of spouses and co-wives left with large numbers of children from the marriages; grandparents with the grandchildren [left behind by] two or more deceased children; young siblings caring for younger brothers and sisters;"[184] and orphans that have experienced the death of their (possibly sick or older) foster parents and have been relocated to a third home.

The most common problem among those caring for orphans is the lack of financial resources, particularly when the caretaker is a surviving mother, a grandparent or another relative, or when the orphans are left to fend for themselves. While family friends and NGOs rarely assume responsibility for orphans, children under such guardianship generally express more concern over the lack of parental care than over the lack of money.[112]

Given the enormity of the problem, and in view of the changing patterns of family responses and the paucity of culturally acceptable alternative care models in resource-poor environments, the post hoc "therapeutic" options for action appear to be very limited. The treatment of orphans by the relatives providing foster care is highly variable within a particular community. The majority of orphaned children are being cared for satisfactorily within extended families, often under difficult circumstances. There is little evidence of widespread discrimination against or exploitation of these children by extended family guardians. A significant number demonstrate appropriate concern for the welfare of the orphans in their care; in one study, caregivers indicated that they would seek to negotiate a bride price when the time came for their foster daughters to marry—a sign that the girls were considered part of the family.[172] The fact that community coping mechanisms are changing does not imply that the traditional system of extended family care is on the verge of collapse. However, the emergence of orphan households headed by siblings is an indication that extended families are under stress. The traditional absorption of orphans within the extended family "is becoming more difficult because of the large number of young adults dying. The burden of care and support is falling on the very young and the very old. A number of strategies have been introduced to provide this care and support. Institutions, though popular, are very expensive to run, have limited capacity and only really cater for physical needs. Interventions which simply react to those who present to them may not reach the most needy and may encourage dependency. Community-based orphan care has been identified as the best and most cost-effective way of caring for orphans."[185] Serious efforts must be directed towards supporting extended family caregivers through increased reliance on existing community-based organizations (see box 5). Orphan support programmes may need to be established initially in high-risk-community settings such as low-income urban areas and peri-urban rural areas.[172] Particular attention should be given to those countries seriously affected by AIDS, where the orphan population is growing most rapidly.

Box 5. Responding to the orphan crisis: the role of community-based organizations

"Focus group discussions and interviews were held with 40 orphans, 25 caretakers and 33 other community workers from a rural area near Mutare, Zimbabwe. Orphan concerns included feeling different from other children, stress, stigmatization, exploitation, schooling, lack of visits and neglect of support responsibilities by relatives. Many community members, while recognizing their limitations due to poverty, were already actively helping orphans and caretakers. Extended family networks are the primary resource for orphans, though some relatives exploit orphans or fail to fulfil their responsibilities. Interventions are suggested which support community coping mechanisms by strengthening the capacities of families to care for orphans. Outside organizations can develop partnerships with community groups, helping them to respond to the impact of AIDS, by building upon existing concern for orphan families. They can help affected communities to develop orphan support activities which encourage caring responses by community leaders and relatives and which discourage property-grabbing and orphan neglect. Material support channelled through community groups to destitute families at critical times can strengthen family coping mechanisms. Income-generating activities should build upon communities' existing capabilities and benefit the most vulnerable orphan households. Some communities are responding to the AIDS disaster by adaptations to cope with devastating changes taking place in their communities."[a/]

Among those programmes already operating, few have received much detailed coverage. Families, Orphans, and Children under Stress (FOCUS), established in Zimbabwe in 1993, is one example of a community-based orphan visiting programme. Soon after the programme was initiated, "twenty-five volunteers identified 300 orphan households. During one year, volunteers made 1,725 home visits, and 123 households received an average of US$ 11 in material support or school fees. In 292 orphan households there were 702 orphans, [accounting for] 14.7 per cent of the children under 15 years in the area. The rate of parental deaths was increasing, with 3.5 per cent of households in the area having a parental death in 1994." Forty-five per cent of the caretakers were grandparents, and 33 per cent of those caring for orphans were over the age of 60. "Three per cent of orphans were cared for by adolescent siblings. The poorest orphan households were those in receipt of school fees, with out-of-school children or with an older sibling as caregiver. Community members initiated activities to help orphans."[b/] "In the last six months of 1996, the FOCUS programme's 88 volunteers made a total of 9,634 visits to 3,192 orphans in 798 families at an average cost of US$ 1.55 per visit."[c/]

This type of programme is "targeted, effective and replicable".[b/] "The key elements of such programmes have been identified. They need to be implemented by a community-based organization ... [or organizations] within a defined community."[c/] For example, "local churches and women's groups can be mobilized to administer programmes which provide support to the poorest orphan households".[b/] "Volunteers should be selected from within the community. They need to be trained and supported as they enumerate orphans, identify the most needy and carry out regular visits. The volunteers should keep records of all their activities. These records can then be used as a basis for monitoring the programme. In order to cope with the increasing number of orphans in resource-poor settings like Zimbabwe, it is essential that such programmes be replicated and scaled up. This is not only an economic necessity but also a way of providing appropriate and effective services to those who need them."[c/]

Sources: [a/] G. Foster and others, "Perceptions of children and community members concerning the circumstances of orphans in rural Zimbabwe", *AIDS Care*, vol. 9, No. 4 (1 August 1997), pp. 391-405; [b/] G. Foster and others, "Supporting children in need through a community-based orphan visiting programme", *AIDS Care*, vol. 8 (1996), pp. 389-404; and [c/] R.S. Drew, C. Makufa and G. Foster, "Strategies for providing care and support to children orphaned by AIDS", *AIDS Care*, vol. 10, No. 1, supplement (April 1998), pp. S9-S15.

CHAPTER 7
CHANGING STRUCTURES AND FUNCTIONS OF FAMILIES AFFECTED BY HIV/AIDS

The AIDS epidemic in Africa has evolved during a period in which family structures have been changing in response to urbanization, political events, civil conflicts and economic crises. The appearance of AIDS has accelerated these transformations, and in those countries in which the epidemic has not abated or has been inadequately addressed, its impact on families is such that it has begun to resemble a smouldering social genocide. The full impact of this process, hidden in a litany of statistics, is increasingly taking on a human face in the reports of journalists.[186, 187]

The social relations of individuals living with and families affected by HIV/AIDS often undergo significant modification. A study on the socio-economic future of children and families affected by HIV/AIDS was carried out in Côte d'Ivoire as part of a multi-centred, multidisciplinary project. The study included 120 families with at least one child. It was found that significant modification and restructuring had occurred at the household level, making these families more vulnerable economically and in the management of daily needs and social life. Women and children were most seriously affected. Whether widowed or separated, women were more likely to be single parents with limited incomes. Children suffered psychological problems resulting from the illness or death of one or both parents and were exposed to the problems of the adults with whom they lived. The living conditions of children orphaned by AIDS or residing with surviving seropositive parents were often difficult. While families continued to represent a substantial source of assistance for the ill, such support typically decreased over time.[188] The conviction that the family can resolve all problems is beginning to weaken. The establishment of support organizations for AIDS patients and their families may enable them to cope more effectively with the disease and its consequences.

Research on HIV infection within the family has focused on sexual partners and vertical transmission; the scope of the problem of multiple infections and clustering of HIV among family members has been less extensively explored. Families tend to "share their lifestyles, their intimate and extended environment ... and nearly always their infecting and symbiotic organisms. Above all they share their social environment, its vital roles and relationships, its pressures and pleasures, modes of conduct, value systems, sexual behaviour, mores and beliefs."[189] As a consequence, among affected kinship groups there are likely to be multiple members living with HIV/AIDS within the nuclear and extended family. In a study from the United States on HIV-positive women and high-risk seronegative women, a third of the respondents reported having multiple family members with HIV, most often siblings.[190]

New household structures are emerging in Uganda as a consequence of AIDS. Family households are now being headed by widows, widowers, single women, children under the age of 18, and orphans who have lost both parents and either are unwilling to be looked after by extended family members or have no close relatives to provide assistance.[78] Widows are now heading households because the traditional practice of levirate is disappearing; the men who would once have inherited a deceased brother's wife as a matter of course are no longer willing to take these women in, fearing that they might contract HIV from them. Widowers are also finding it difficult to remarry because women are afraid of being infected by them.[61]

Proximity to others in the family network has been an important component of family capital in many traditional societies, particularly

when other resources are limited. In some instances, owing to circumstances or custom, members of the family network may be dispersed and unavailable for social support, respite, or orphan care. In a study of a group of HIV-infected women in Rwanda it was found that 30 per cent of the women and 44 per cent of their partners had no relatives nearby. Almost a third of the women had no partners willing or able to take care of the children when the women died.[191] A report from Uganda describes how newly married couples move away from their parents' villages to other villages to ensure independent living. It is probable that with the high internal (rural-rural) migration in Uganda, some orphans find themselves without close relatives in the vicinity to help.[192] The virtual absence of family support has serious psychological, economic, social and health implications for the development and growth of these orphans and those under their care.[61, 193]

7.1 Changes in mortality

A little more than a decade ago, AIDS began to have a noticeable demographic impact. Evidence from national census data indicated that AIDS was starting to have a serious but localized impact on the population structure in Uganda as early as 1991. A report published in 1997 affirmed that the demographic effects had occurred much earlier than previously estimated; that negative population growth was evident at a local, subdistrict level but not yet at the district or national level; and that the epidemic had had a greater impact on the numbers of children than previously predicted, owing as much to changes in fertility as to increases in mortality.[194]

A recent United Nations report includes projections that convey the devastating impact of HIV/AIDS, particularly in the seven African countries most seriously affected. By 2015, Africa is expected to have at least 91 million, or 10 per cent, fewer people than it would have had in the absence of AIDS. While population growth is expected to rise from 74 million in 2000 to 78 million in 2050, "outright reductions in population are projected for Botswana, Lesotho, South Africa and Swaziland".[21] In Botswana, where a newborn's life expectancy has plummeted by more than 25 years over the past decade, and in other countries such as Lesotho, Mozambique, South Africa, Swaziland, Zambia and Zimbabwe, it is predicted that by 2005-2010 life expectancy at birth will have declined to levels recorded in the 1950s, 1960s or earlier.[195]

The impact of HIV/AIDS on population growth is becoming increasingly evident in southern Africa and other areas of the region. South Africa's annual population growth, which was 2.1 per cent during the period 1990-1995, is expected to decline by 0.3 per cent annually during the period 2005-2010. Within the context of this study, an analysis of the numbers of families newly affected by HIV/AIDS indicated that between 2001 and 2003 the numbers of HIV/AIDS-free families declined by 0.8 to 5.8 per cent in Botswana, Lesotho, Namibia, South Africa, Swaziland and Zimbabwe (see figure XIX). Statistics for the reporting period 2000-2005 suggest that AIDS accounts for 20 to 35 per cent of under-five mortality in Botswana, Namibia, South Africa, Swaziland and Zimbabwe (the countries with high HIV prevalence). In Botswana, under-five mortality is expected to reach nearly 57 per 1,000 live births, compared with a rate of 35.5 per 1,000 were AIDS not a factor.[21] The emergence of such a dramatic demographic impact at this stage highlights fundamental aspects of the interdependence of HIV infection and demographic growth not previously recognized or recorded, as well as the need to target preventive interventions to youth in developing countries.[194]

In the absence of AIDS, women are more likely to outlive their husbands than men are to outlive their wives in most countries. The magnitude of the difference between maternal and paternal orphan rates is a function of the age differential of couples; the age of women at marriage; the probability of death during pregnancy, delivery and the post-partum period;

and age-/gender-specific mortality rates for adults in a particular setting. In African and other developing country settings with low levels of HIV infection, or early in the course of the epidemic, there is a 1.5-to-1 ratio of paternal orphans to maternal and double orphans; this was the estimated ratio calculated for 26 sub-Saharan African countries in a 1990 projection using the United States Census Bureau model.[196] With the increased prevalence of HIV, women's greater vulnerability to HIV infection, and possibly the combined adverse effects of malnutrition and breastfeeding[8] in such a context, a reversal is occurring; by 2010 the ratio is expected to be 0.8 to 1, with the shift almost entirely attributable to maternal and double AIDS deaths. Regardless of which model is used, the number of maternal orphans is rising rapidly.[45]

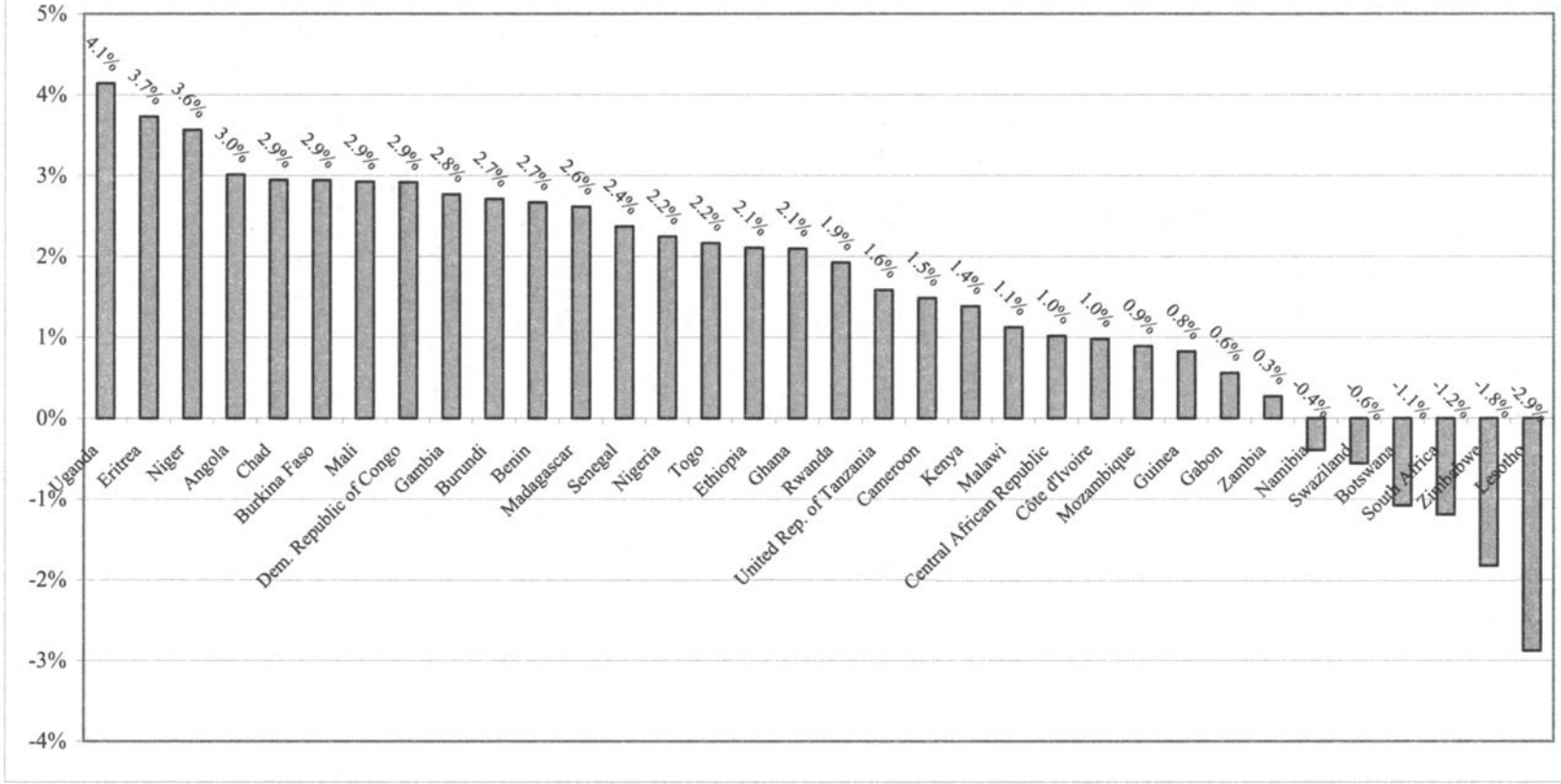
Even in the absence of clinically defined AIDS, HIV infection in many areas is associated with, and most likely a determining factor in, other primary causes of death. In a four-year prospective study in a rural Tanzanian community with a population of 20,000, mortality rates were 15 times higher among HIV-infected adults than among those who were HIV-negative. The mortality probability among 15- to 60-year olds was 49 per cent for men and 46 per cent for women, and life expectancy was 43 and 44 years respectively. By their second birthday nearly one quarter of the babies of HIV-infected mothers had died, a rate 2.5 times higher than that for children of HIV-negative mothers. Mobility prior to death was common, with infected migrant labourers returning to their places of origin to avail themselves of multiple familial sources of care and support during the period of prolonged illness, and to be where they wished to die. The mobility of household members before and after the death of infected individuals was also high. Household dissolution occurred among 44 per cent of the families once the head of the household had died.[197]

7.2 Parentification and child-headed families

"Some family systems and circumstances may increase the risk of the inappropriate and premature assumption of adult roles by children or adolescents before they are emotionally or developmentally able to manage these roles successfully. This process has been termed parentification and is defined as a situation in which children are prematurely forced into fulfilling parental roles and assuming adult responsibilities."[198] Parentification may involve the child assuming a guilt-laden caretaking role as a confidante, helper and primary source of support to fulfil the unmet needs of the parent.

Nearly all of the research undertaken to assess the impact of parents' disclosure of their HIV seropositivity or AIDS status on the behaviour and mental health of children and adolescents comes from North America. Predictors and outcomes of parentification among adolescent children of parents with AIDS have been identified and assessed. One study found that adult role-taking was associated with the mother having HIV/AIDS, female adolescents, and higher levels of parental drug use. Greater parental AIDS-related illness predicted more spousal and parental role-taking. Parental drug use predicted more parental role-taking. In a subsequent follow-up of 152 adolescents, the impact of parentification on later adolescent psychological adjustment was examined. Adult role-taking predicted more internalized emotional distress. Parental role-taking predicted externalized problem behaviours, including sexual behaviour, alcohol and marijuana use, and conduct problems.[199]

Figure XIX. Annual change in the percentage of HIV/AIDS free families in 34 sub-Saharan African countries between 2001 and 2003



Sources: Data for the models and analysis were obtained from the 34 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2002 Revision* (CD-ROM) (New York, 2003) (United Nations publication Sales No. E.03.XIII.8).

7.3 Social and family capital

Most families in rural areas of the developing world have traditionally shown a high degree of self-reliance in coping with disease and illness. HIV/AIDS, having introduced a new set of challenges threatening the integrity and functioning of the family, has had an impact different from that of other diseases in terms of the accumulation, maintenance and depletion of social and family capital. It may positively or negatively affect trust, communication and traditions within the family and consequently reinforce or undermine intrafamily bonds. In the absence of specific policies and succession planning for families affected by HIV/AIDS, the three epidemics almost invariably have a negative effect on the productive capacity, knowledge base and physical assets of these families, and on their capacity to invest in the future through the education of the younger members.

Family capital is likely to be the most accessible form of social capital available to people with HIV/AIDS and their affected families. However, the potential advantages deriving from the exchange of such capital may be unrealizable if family decision makers react to the disclosure of HIV seropositivity with anger and rejection. Access to family capital may also be denied if the bureaucracies controlling financial resources to which families affected by HIV/AIDS are entitled are overwhelmed, inefficient or corrupt.

Family capital tends to diminish rapidly when a family is affected by HIV/AIDS. Remittances are lost when an infected labour migrant returns to his or her household for care, and the family must spend additional time and money in the provision of such care. Other family capital investments such as the education of children are diverted to caring for the person living with AIDS and maintaining the existing family resources. Often, the bonds of trust and affection are severely strained both within and beyond the family as a result of discrimination and stigmatization. Stress in such circumstances adversely affects the course of the disease, accelerating the loss of family capital as the burden on the family is increased.

Family capital may also be misappropriated or misused by some members of the family network, resulting in an increase in intrafamily conflict. For example, extended family members may violate the inheritance rights of the spouse or children of a person who has succumbed to AIDS. In other instances there may be bureaucratic obstacles to families gaining access to health benefits, life insurance or other entitlements, or access may be denied altogether.

In the presence of HIV/AIDS, the "family trust and emotional support" component of family capital is very elastic. To the extent that the discrimination and stigmatization associated with AIDS permeates and is unchallenged within the family, there is less family capital for the person living with the disease to draw upon. Such considerations guide decisions regarding whether, when, to whom, and how to disclose one's HIV-positive status to family members. To the extent that the family members have accurate knowledge and have been sensitized to the needs of the person living with HIV/AIDS, family support (and therefore family capital) is strengthened, and the family can begin to plan for the future.

A controlled study undertaken to evaluate an intervention designed to improve behavioural and mental health outcomes among adolescents and their parents with AIDS has demonstrated that such interventions can reduce the long-term impact of parents' HIV/AIDS status on themselves and their children. "Adolescents in the intensive intervention condition reported significantly lower levels of emotional distress, of multiple problem behaviours, of conduct problems, and of family-related stressors and higher levels of self-esteem than adolescents in the standard care condition. Parents with AIDS in the intervention condition also reported significantly lower levels of emotional distress and multiple problem behaviours. Coping style, levels of disclosure regarding serostatus, and

formation of legal custody plans were similar across intervention conditions."[96]

Another intervention programme was developed specifically to enhance social capital.[36] A "structural intervention" was devised to strengthen family functioning and interfamily bonds in the community. By fostering strong relationships within and between families in a community with high rates of violence, drug abuse and HIV infection, the programme sought to improve the quality of neighbourhood life and influence the social determinants of individual risk behaviours. In addition to fostering closer relationships between children and their parents, the programme worked to help participating families develop closer relationships with other participating families and with student and faculty volunteers from a local university. The programme is currently being evaluated.

7.4 Changing responses of the family network and community

It is commonly assumed that in Africa the extended family provides a safety net for individuals in times of need, but AIDS may challenge that assumption. A small prospective study[99] of the care provided to 30 AIDS patients (17 women and 13 men) by their families in Uganda revealed that the majority of extended families offered only limited support. Among the various reasons cited by the caregivers were the lack of food, insufficient funds for medications, and the caregivers' other family responsibilities. Among the non-household relatives of those who died during the study period, one third had refused requests to help with patient care because of poverty or other commitments. However, in all but one instance, extended families did provide assistance for the funerals.

Research findings suggesting greater inaccessibility to resources within the family network are supported by studies in Kenya affirming that because of inadequate information about the disease and care expectations, people with AIDS typically face feelings of ambivalence or rejection from others. Those in the latter category generally express a preference for institutional as opposed to home-based care. Poverty itself is a barrier to providing adequate home care, even among families willing to do so. In the final analysis, most or all of the burden of care is borne by the primary unit (the immediate family), and particularly by the women, who ultimately carry the load with limited resources. Professional guidance in caring for AIDS patients is crucial but is seriously lacking at the family and community levels. The vast majority of caregivers have not had appropriate training and are concerned about their lack of knowledge and relevant skills, but assume responsibility for patient care nonetheless. Counselling and social support are also important requisites for home-based care but are conspicuously lacking in the concerned communities.[200]

Family networks and self-identified barriers to support were studied among more than 200 people with HIV/AIDS in New York.[118] It was found that those living with the disease had fewer than two sources of close support on average. Women were more likely than men to rely on children for support. Male IDUs and MSM "relied on friends and traditional family almost equally, while men at risk for HIV via heterosexual contact relied more on traditional family sources. Barriers to support included interpersonal costs, lack of access, lack of acceptance, lack of intimacy, negative interactions and fear of disclosure. ... If efforts to promote family involvement in patient education and other caregiving activities for people with HIV/AIDS ... are to be successful, clinicians need information concerning [infected individuals' family networks and the barriers these individuals] face in obtaining support."[118]

In developed countries, the major reasons why the family is not a principal part of the support network for MSM living with HIV/AIDS include the family's lack of acceptance of homosexuality and a male member's relationship with a same-sex partner; the stigma attached to AIDS; the inability of

family members to communicate openly about homosexuality and AIDS; the lack of competence among family members in dealing with HIV issues; and parents' overprotective, infantilizing behaviour. A sibling, most often a sister, is the family member to whom the homosexual man with AIDS feels closest and from whom he is most likely to seek support.[201] A similar situation prevails in some developing countries such as Mexico.[73] "Between social support and discrimination, many more 'ambivalent' behaviours (neither fully supportive nor discriminating) are displayed by family members and friends. Fear, pre-existing family conflicts and prejudice nurture these negative responses. Family responses and the processes to which they give rise also differ depending on whether or not a male or female household member is affected. ... Framed by a value system that strongly differentiates men from women, sexual activity is encouraged among young men and restricted among women. Linked to the expression of such strongly defined gender roles is an open rejection of homosexuality."[73] The study on which these observations are based noted that "images of HIV and AIDS and dominant cultural values also influenced the way in which the families of gay men reacted to the news that a son [had] HIV disease. Of particular importance in determining the form of such responses was the way in which the family had previously reacted to the news that one (or more) of their sons was homosexual."[73]

In some communities families dissolve or are deconstructed by AIDS, as indicated in an earlier reference to the Tanzanian study, which showed that in almost half of the households in which the main provider had died, the family was unable to stay together as a nuclear, mutually supportive unit.[197]

7.5 Resilience: fertility and childbearing within the HIV/AIDS context

Several studies conducted in different parts of the world during the mid- to late 1990s indicated that HIV-positive women had lower fertility rates and a higher incidence of failed pregnancies.[51, 52, 53] Not very many years ago it was almost unheard of for a woman who knew she was infected with HIV to attempt to become pregnant. Most women who were aware of their seropositivity were not willing to risk the 25 per cent chance of passing the virus on to their offspring.

Increasingly, there are wide variations in the range of reproductive choices made by women and couples who know that at least one partner is HIV-positive. Effective drug regimens have made it possible for an HIV-positive woman to reduce the probability of infecting her child to almost zero, providing her and her partner with enhanced childbearing options.[202]

Armed with this information, a small but increasing number of HIV-positive women are deciding to have children. However, many worry about the uncertain future that comes with a life-threatening disease. They are concerned about their children's health as well as their own. Although a vast majority of the children are thriving, it is too early to tell whether the powerful antiretroviral drugs taken by the women during pregnancy will have long-term effects on their offspring. The women also worry about disclosure of their HIV status and the associated stigmatization.[203]

The reduction in MTCT is one of the few success stories in the 20-year history of AIDS. The CDC estimates that 6,000 HIV-infected women give birth in the United States every year, and most are receiving some kind of antiretroviral therapy. In the era before medication was recommended for pregnant HIV-infected women, 1,000 to 2,000 babies were born with the virus each year. Between 1992 and 1999 the numbers declined significantly, and currently about 300 to 400 HIV-infected infants are born annually in the United States.[84]

In developing countries as well, in spite of high levels of anxiety about AIDS, the risk of HIV infection is not always associated with the

act of conceiving children, nor has this association necessarily influenced actual behaviour or family-size preferences, although "the threat of contracting HIV [has] led to a decision to have fewer children. Many [have] also worried about leaving orphans for others to look after and the costs which might be incurred in taking over the care of orphans left by others. A related reason for limiting fertility [has been] the hope that orphaned children would be better cared for if there were fewer of them."[95] In some settings, women or couples will undergo voluntary sterilization[204] or medical termination of a pregnancy.[51]

In a nationally representative probability sample of 2,864 HIV-infected adults receiving medical care within the contiguous United States in early 1996, 28 to 29 per cent expressed a desire to have children in the future. Among those who wanted children, 69 per cent of the women and 59 per cent of the men actually expected to have one or more children at some point. The proportion of HIV-infected women who wished to have a child someday was somewhat lower than the overall proportion of women in the United States who wanted a child. The fertility hopes and expectations of HIV-infected individuals do not always match those of their partners; as many as 20 per cent of HIV-positive men who want children have partners who do not. Generally, HIV-positive men and women who wish to have children are younger, have fewer children, and report higher levels of physical functioning or overall health than do their counterparts who do not want to have children, "yet the desire for future childbearing is not related to measures of HIV progression".[202]

HIV-positive men and women who expect to have children "are generally younger and less likely to be married than those who do not. Multivariate analyses indicate that black HIV-infected individuals are more likely to expect children in the future than are others. While HIV-positive women who already have children are significantly less likely than others both to desire and to expect more births, [a] partner's HIV status has mixed effects: women whose partner's HIV status is known are significantly less likely to desire children but significantly more likely to expect children in the future than are women whose partner's HIV status is unknown. Moreover, personal health status significantly affects women's desire for children in the future but not men's, while health status more strongly influences men's expectations [of having] children."[202]

The advent and availability of MTCT therapy and safe, affordable breast-milk substitutes have not eliminated the stresses associated with childbearing among women who are HIV-positive. A group of HIV-infected women in Thailand experienced substantial changes within their families over a two-year period following the birth of a child, facing such challenges as "partner illness or death, family separation, reduced family income, shifting responsibilities for childcare, and signs of depression and isolation".[203] A comparison of baseline and follow-up data indicated that "more women were living alone (1 per cent versus 6 per cent ...), fewer women were living with their partners (98 per cent versus 73 per cent ...), and 30 per cent of families had reduced incomes. ... Most children (78 per cent) were living with their mothers, but only 57 per cent of the HIV-infected women were the primary caregivers."[203]

CHAPTER 8
TRADITIONAL AND OTHER FAMILY PRACTICES AFFECTING VULNERABILITY TO HIV

In all cultures, traditional practices promote bonding and strengthen relationships within and between families, and are part of the community lore and institutions. They constitute an integral part of each stage of the family life cycle, linking the family to the larger community. Traditional practices may be perceived as beneficial, neutral or harmful. Many have arisen from an empirical or culturally defined need to increase social and/or family capital, particularly by strengthening relationships within the clan, between families, or in the community. They often mark rites of passage, celebrating or otherwise validating the progression from one stage of life to another, and may also represent a means of "protecting" individuals and families against adverse forces or circumstances. The present chapter offers an examination of marriage and sexual practices and the traditions and symbols linked to the various rites of passage, including the death of a spouse, as they may relate to HIV/AIDS. Some traditional practices, such as child marriage and levirate, are thought to facilitate the spread of HIV.[205] Others, such as male circumcision, may be beneficial.[206]

Since the rapidly spreading AIDS epidemic was first identified in some areas as far back as the late 1960s and early 1970s,[207] researchers have tapped into an extensive body of social, anthropological and demographic research, further supported by several decades of DHS and fertility surveys using common methodological instruments and sampling techniques. With the wealth of data, particularly as it applies to traditional practices, it is important to be aware of the diversity of methodologies and to avoid drawing premature conclusions based on one or another methodological approach. An ecological approach, such as that applied in the DHS, the MICS and much of the analysis in the present publication, involves comparisons across populations. Other methodologies, both quantitative and qualitative, involve an analysis of the characteristics and behaviour of individuals. As a consequence, broad statements about the pattern of HIV/AIDS in Africa must always be qualified in acknowledgement of the wide variation in cultural patterns, traditional practices, and family structure and functions within different ethnic groups. While the DHS data is broken down geographically and often ethnically, comparable information is not available from the UNAIDS estimates of HIV prevalence or children orphaned by AIDS, limiting the range of possible analysis of ethnic variations and traditional practices. Within countries, HIV serological surveys should be included as part of the household survey data collection, as has been the case in the national DHS for Mali and Zambia.

8.1 Marriage

Marriage is the entry point into family formation and the start of a new family cycle. While early (adolescent) marriage for women is declining, this traditional practice remains prevalent in many developing countries, and the young women are still expected to bear a child as soon as possible.[208, 209] A woman's age at the birth of her first child serves as an indirect indicator of her age at marriage; the average figures for both vary widely among women in South-East Asia, Western Asia, and sub-Saharan Africa. For example, among women currently between the ages of 25 and 29, by which time most women in the developing world are married, the median age of marriage ranged from 17 years or less in such countries as Niger (15.3), Bangladesh (15.4), Chad (15.9), Yemen (16.6) and Nepal (17.0), to more than 20 years in such countries as Kenya (20.3), Rwanda (21.0), the Philippines (22.7), and Jordan (23.1).[210] The

proportions of those who experienced their first delivery before the age of 18 were as high as 47.3 per cent in Guinea, 45.4 per cent in Chad, 43.6 per cent in Bangladesh, and 42 per cent in Uganda, and as low as 10.4 per cent in Cambodia, 17.8 per cent in Namibia, and 18.8 per cent in Togo.[211]

Marriage, pregnancy and childbirth prior to social and biological maturity are generally considered hazardous for adolescent women, particularly in situations in which nutritional levels are poor and maternal health services are inadequate.[212] Young women in this category may also be at increased risk of acquiring HIV. Those living in settings in which a significant proportion of men engage in extramarital sexual activity may be more likely to acquire STDs from their husbands—a risk compounded by the increased vulnerability of the immature reproductive tract to infection.[213] Data from several countries in Africa indicate relatively high levels of infertility, a consequence of the increased incidence of genital tract infections among girls for whom sexual activity was initiated at a relatively young age.[214]

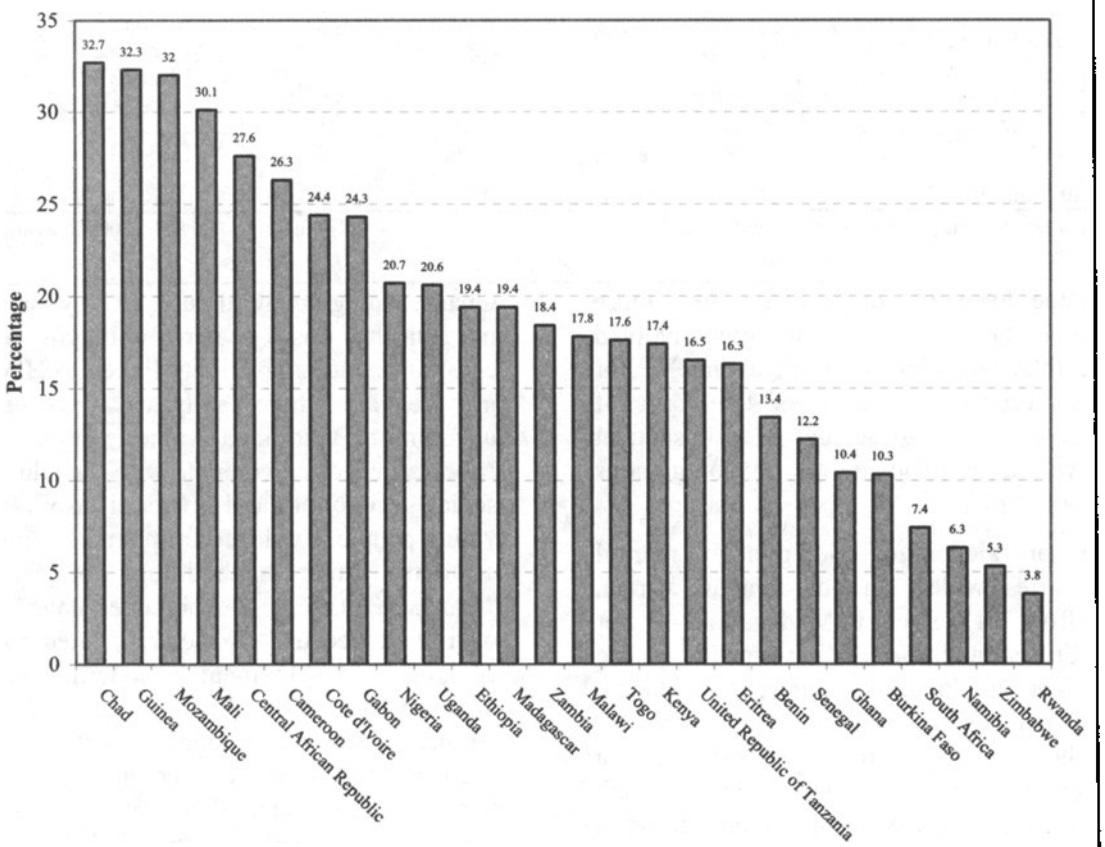
Even in traditional societies, child marriages tend to be less stable than marriages contracted at the time of biological and social maturity. In most traditional societies girls first experience sexual activity within marriage, though for many this may occur before or soon after the onset of menses, with brides as young as 10 or 11 years of age. Research undertaken among an adolescent clinic population in Ethiopia[215] indicated that pre-menarche sexual initiation had occurred for 40 per cent of the girls. Early marriage may be associated with limited education, marital discord, and divorce.[216] A lower age at marriage may also be associated with infertility, and with child prostitution, often as a consequence of the child-wife running away and having no means other than prostitution to support herself.[217]

Studies in Ethiopia[215] indicated that 42 per cent of prostitutes, compared with 9 per cent of those still wed to their first husbands, were married before the age of 13. Nearly 70 per cent of the women engaged in prostitution had been sexually active before menarche, compared with half that number among a control group. It may be inferred, given that half of all prostitutes were married for less than five years, that a large number began prostitution as children.[217]

Rates of child marriage are very high in Ethiopia, particularly in rural areas, and first coitus traditionally occurs at the time of or soon after marriage. According to a study of the sociocultural background of early child marriage in this African country, four major factors that have sustained the tradition are the urgency to utilize the immediate capacity of parents to establish a family for their children; the desire to expand kinship relations for protection and economic security; conformance with the norms of a compelling, age-old tradition; and the patriarchal subordination of women and consequent high value placed on virginity.[218]

While there is apparently solid clinical and epidemiological evidence of vulnerability to HIV and other STDs among very young women, from a population perspective this group does not appear to make a significant contribution to the variation in the rate at which families are newly affected by HIV/AIDS. The national variations among the 25 countries with suitable recent data on the median age of marriage among women 25 to 29 years of age are not statistically correlated with this HIV/AIDS indicator. National DHS studies show significant variations in the timing of the first sexual encounter among women (see figure XX). The proportions of women aged 25-29 years who had their first sexual encounter by the age of 15 vary widely in sub-Saharan Africa, ranging from 3.8 per cent in Nigeria and 5.0 per cent in Namibia to 32 per cent or more in Chad, Guinea and Mozambique. An analysis of these national DHS data reveals no correlation between early sexual experience and either the incidence rate of families affected by HIV/AIDS or adult HIV prevalence. However, in two of the three DHS studies in which the HIV status of adult household members was ascertained, HIV prevalence was significantly elevated among those women who had had their first sexual encounter before the age of 16 (see table 4).

Figure XX. Percentages of women aged 25-29 years whose first sexual encounter occurred by age 15 in 26 sub-Saharan African countries, 1992-2002



Source: Data from the 26 national Demographic and Health Survey from 1992 through 2002 as noted in Annex II to the present publication.

An additional factor shown to affect the marital risk of HIV/AIDS for adolescent and young women is the age difference between these women and their sexual partners. In a large Ugandan study of 6,177 adolescent and young women who had ever been sexually active, there was a doubling of the risk of HIV infection among those 15 to 19 years of age who reported that their sexual partners were ten or more years older, in comparison with those whose partners were only up to four years older.[219]

Serial marriages play an important part in marital mobility and the dynamics of the HIV/AIDS epidemic in areas of Uganda and probably elsewhere. Serial marriage can be defined as "participation in a sequence of regular partnerships or unions. By this definition, males in polygamous unions are involved in the practice of serial marriages in that they go

Table 4. HIV prevalence among women aged 15-49 years in Burkina Faso, Ghana and Kenya by age at first sexual encounter, 2003

Country	Age at first sexual encounter and HIV prevalence				Chi-square	*p* value
	<16	16-17	18-19	20+		
Burkina Faso	1.5%	2.4%	2.7%	0.3%	8.3913	<0.05
Actual number	938	1 529	744	293		
Ghana	4.5%	2.3%	3.6%	2.2%	12.6653	<0.01
Actual number	1 103	1 234	1 105	859		
Kenya	12.4%	9.3%	9.7%	6.0%	13.3484	<0.005
Actual number	940	648	515	392		

Sources: National Demographic and Health Surveys for Burkina Faso, Ghana and Kenya (2003), available at http://www.measuredhs.com/.

through the formation of regular unions more than once in their lifetime and are often involved in more than one such union at a time."[29] For women, "serial marriage takes the form of transition from first to second and subsequent unions within a monogamous or polygamous framework".[29]

The prevalence of polygynous marital unions varies widely in sub-Saharan Africa, ranging from 3.4 per cent in Madagascar, 6.7 per cent in Eritrea, and 13.5 per cent in Ethiopia to 52.4 per cent in Togo, 53.3 per cent in Guinea, and 54.6 per cent in Burkina Faso.[220] Overall, among the 26 countries for which suitable data on different types of marital unions are available, there is no correlation between polygynous unions and the rates at which families are newly affected by HIV/AIDS. As already noted, though, while different factors may not be significantly associated with the HIV/AIDS indicators when analyzed in connection with all countries in sub-Saharan Africa, within individual countries in which household data link HIV status with specific characteristics of the household or household members, there may or may not be correlations that are statistically significant, as noted for Burkina Faso, Ghana and Kenya (see table 5).

The analysis undertaken within the context of this study has demonstrated that the relationship of HIV status to polygyny is not significant in Ghana; is negatively, though weakly, significant in Burkina Faso (where polygyny is very common); and is positively linked to HIV status in Kenya, where polygyny is relatively uncommon. Traditional values, obligations and expectations often compete with the educational, social, economic and material aspirations of young people. Evidence from studies employing a focus group methodology indicates that "marriage customs and practices have changed over time because of factors related to socio-economic development, modernization and Western culture".[61] Among these factors are "limited resources coupled with economic problems that have resulted in a high cost of living and high unemployment rates, especially among youth; modernization and the influence of Western cultures; high bride-wealth; intermarriages between ethnic groups; education; modern religions; society's acceptance of cohabiting; lack of parental guidance; lack of trust and confidence among married couples; [and] promiscuity and AIDS".[61] In Uganda, a number of recent changes in courtship and marriage practices have been closely linked to the AIDS epidemic. "However, many customs have persisted, such as parental participation in the introduction and negotiation for children's marriages, bride price, dowry, circumcision of boys before marriage, fining boys who elope with girls and rewarding virginity at marriage."[61] The societies that have

Table 5. HIV prevalence by type of marital union for men and women in Burkina Faso, Ghana and Kenya, 2003

Type of marital union for women					
Country	Polygynous	Not polygynous	No current union	Chi-square	*p* value
Burkina Faso HIV+	1.2%	2.0%	2.6%		
Total number	1 546	1 558	982	6.8617	<0.05
Ghana HIV+	3.3%	2.8%	2.4%		
Total number	724	2 468	1 905	1.7164	Not significant
Kenya HIV+	11.4%	7.2%	9.8%		
Total number	326	1 571	1 254	9.3786	<0.01
Type of marital union for men					
Country	Polygynous	Not polygynous	No current union	Chi-square	*p* value
Burkina Faso HIV+	1.5%	3.2%	.0.9%		
Total number	372	1 181	1 512	19.5247	<0.001
Ghana HIV+	1.6%	2.4%	0.6%		
Total number	222	1 759	2 066	21.7747	<0.001
Kenya HIV+	11.9%	6.5%	2.4%		
Total number	126	1 227	1 498	42.0500	<0.0001

Sources: National Demographic and Health Surveys for Burkina Faso, Ghana and Kenya (2003), available at http://www.measuredhs.com/.

retained such traditions wish to perpetuate them because they are regarded as good.[61]

VCT and disclosure often affect the whole family and the way it functions. In a number of countries it is traditional for a family, before agreeing to a marital union, to vet another family to ensure that the latter has an unblemished background and that none of its members has ever had a serious or stigmatizing disease. As a result, in West Africa, for example, individuals with AIDS have been either taken into hiding or rejected by their own families.[22]

In Uganda, AIDS knowledge and awareness may increasingly affect the choice of a partner.

Marriage or other consensual unions based on "love at first sight" may gradually be abandoned in favour of greater caution and more extensive research on the background of potential suitors. HIV testing centres in Kampala are reporting growing numbers of urban and educated young people having HIV serology tests before making a marriage commitment, primarily to avoid HIV infection from a previously infected spouse. Tellingly, it is now the individuals concerned, rather than their parents, who do the research on potential partners.[61] "Parents and society are

likely to be tolerant and understanding of delayed marriages in future. They would rather have unmarried boys and girls than their coffins. Once this trend is accepted, delayed marriage may lower the very high fertility rates in Uganda."[61]

It is evident that Ugandans, with their relevant community-based research and experience, are aware of the profound impact AIDS has on marriage as an institution. Fear of potential partners being seropositive is holding young people back from marrying, and this may have a number of consequences. Promiscuity appears to be declining in some areas,[221] and lower STD levels are reported among adolescents in one region with high HIV prevalence, perhaps as a result of reduced sexual activity.[222]

Another consequence of AIDS is its impact on marital stability. Faithfulness to one partner (zero grazing) is apparently becoming more prevalent. Although the elder participants in various focus group discussions have been divided over the moral implications of separation and divorce in the face of AIDS, the young have unanimously supported these options. This implies that in the future, society may no longer condemn those spouses who leave their partners because of unfaithfulness in an environment in which fear of AIDS runs high. This change in attitude by society may lead people to seek and maintain permanent relationships with one partner and abandon multiple-partner practices in order to preserve their nuptial unions. Polygamy may also decline in the long run, even among Muslims.[61]

8.2 Sexual practices

Monogamy in marriage for women is a deep-rooted value in most traditional societies, but men generally are not held to the same standard. While much of the success of the efforts to control HIV/AIDS in Uganda has been attributed to zero grazing, at the level of population analysis for the 11 countries* for which DHS data are available the correlations are not statistically significant, though there is a trend showing higher levels of monogamy among men and women being associated with lower incidence rates of families affected by HIV/AIDS. Data from three national DHS studies indicated that HIV prevalence was significantly higher among men and women in Kenya who had had more than one sexual partner in the preceding 12 months (with far fewer women than men having more than one sexual partner); that a similar pattern prevailed among the women but not the men in Ghana; and that while the prevalence of HIV infection among men varied significantly with the number of sexual partners, the pattern was not that of a consistent trend (see table 6). In some sub-Saharan African countries the majority of men have long-term relationships with more than one woman at a time. Factors contributing to or associated with this practice include the inheritance of widows by members of the husband's lineage, the need of men to demonstrate their power and wealth, the inability of women to generate resources without spousal assistance, wide spousal age gaps, and the low age at marriage for females.[208]

Research on African societies shows that at younger ages women are more likely than men to be both infected with and affected by HIV. Biologically and contextually, women are more vulnerable to infection, and insofar as younger women are aware of the increased HIV risk from a contextual perspective, they are also affected to a greater degree. They are aware of and may fear the implications of what was socially, culturally and economically acceptable or tolerated in the pre-AIDS era but has now become life-threatening. Young African women are particularly vulnerable to infection because sexual relations with men are an important means of achieving social and economic status and in some cases are necessary for survival.

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* Benin, Burkina Faso, Ethiopia, Gabon, Ghana, Kenya, Niger, Uganda, United Republic of Tanzania.

Many African adolescents and young adults engage in premarital sexual relationships, either sequentially or simultaneously. Unmarried African males commonly have a "main" girlfriend, whom they expect to marry, and one

Table 6. Sexual behaviour characteristics of men and women who have ever had sex, by HIV status, in Burkina Faso, Ghana and Kenya, 2003

	Number of partners in the preceding 12 months				
	Women		Men		
Burkina Faso	1	2	1	2	3+
Percent HIV+	2.0%	(5.6%)*	2.4%	0.4%	5.2%
Number	2 549	45	1 455	370	77
Chi-square	2.8372		9.3263		
p value	Not significant		<0.025		
Ghana	1	2	1	2	3+
Percent HIV+	3.1%	9.4%	2.0%	2.0%	(-)*
Number	3 412	50	2 177	321	(5)
Chi-square	6.3313		—		
p value	<0.025		Not significant		
Kenya	1	2	1	2	3+
Percent HIV+	9.6%	20.4%	5.4%	9.7%	3.3%
Number	2 166	53	1 700	262	64
Chi-square	6.7906		8.3724		
p value	<0.01		<0.05		

Sources: National Demographic and Health Surveys for Burkina Faso, Ghana and Kenya (2003), available at http://www.measuredhs.com/.

* The use of parentheses here denotes reference to a relatively small number.

or more other girlfriends, for whom there are no such expectations; some women employ similar strategies.[223]

In Cameroon, focus group data have been used to identify "popular types of premarital sexual relationships, and to examine gender differentials in the motivations for engaging in such relationships and in perceptions of the factors that affect the marriage prospects of these premarital relationships. Economic need leads many young women to use premarital sexual relations for economic support, despite high levels of HIV infection."[223]

There is some evidence from Uganda that the zero-grazing/be-faithful educational message for AIDS prevention seems to be working, and apparently certain traditional sexual practices that increase the risk of HIV infection are declining or are expected to decline among a number of ethnic groups. Among the practices many believe are likely to be abandoned owing to fear of HIV infection are sexual indulgences at the last funeral rites (Baganda), all brothers sharing one wife (Banyakore), and sexual orgies at circumcision ceremonies (Bagisu). Already, the last funeral rites among the Baganda are no longer celebrated as in the past because the number of funerals has become too large. Those who perform circumcisions now change blades for each individual. Among the Banyakore the practice of polyandry has been condemned by local civic and religious leaders.[61]

8.3 Rites of passage

Rites of passage marking the critical transitions from one stage to another in the family life cycle (from birth through death) are found in all societies and are characterized by ceremonies, symbolism and specific ritual acts. They may be celebrated or performed within the family, linked to specific institutions and religious practices, or conducted among age cohorts of the same sex. Male circumcision and female genital mutilation are among those traditional rites that may have some bearing on HIV/AIDS in many societies. As with other traditional practices, the form, timing and circumstances of their occurrence vary widely.

8.3.1 Male circumcision

A hypothesis concerning the possible role of male circumcision in disease protection was presented early in the course of the HIV epidemic to explain the wide variations in HIV prevalence rates in Africa. This hypothesis was supported by the finding that HIV seroprevalence in the general adult population was statistically associated with male circumcision status in 140 geographically distinct locations in sub-Saharan Africa. [224] A poorly designed meta-analysis not only challenged this hypothesis, but claimed to show that circumcision increased the risk of HIV/AIDS.[225] However, a more suitable analysis of the data[226] and all relevant published scientific reports supported the conclusion that male circumcision lowered the risk of HIV infection.[227, 228] Because of the strong association of circumcision with particular ethnic and religious groups, and the observation that the sexual behaviour of circumcised and uncircumcised men differs in some contexts, additional studies were undertaken. The results indicated that the differences in sexual behaviour did not account for the higher risk of HIV infection among uncircumcised men.[229] It was found, however, that the timing of circumcision did influence the risk of HIV infection, with the research showing that pre-pubertal circumcision was protective, whereas post-pubertal circumcision, particularly after the age of 20, was not significantly protective.[228]

As a result of recent enhancements the national DHS have not only had the opportunity to include subsamples of households in which the adult members have been offered HIV tests, but have also (since 2001) been given the option of incorporating an extra module on factors possibly contributing to the variations in HIV prevalence among different countries and communities. HIV prevalence studies and the collection of detailed data on male circumcision, sexual activity and various demographic variables have been undertaken in Burkina Faso, Ghana and Kenya. The overwhelming majority of men in these countries are circumcised (see table 7). However, the rates of circumcision are significantly lower in Kenya, and slightly lower in Burkina Faso, among those aged 15-19 years. This may reflect the timing of circumcision as part of the initiation into "manhood" among some ethnic groups in these countries. While the overall rates of circumcision are similar, there are significant country-level differences in its "protective" effect, which is clearly evident in Kenya but not demonstrated in Ghana, and only seems to be observed in Burkina Faso, where it is not statistically demonstrated (see table 7).

Although religious affiliation affects the circumcision rate, it does not necessarily follow that it will affect HIV prevalence. At least 98 per cent of Muslim men are circumcised, and the same is true for at least 80 per cent of the adult men affiliated with the other formal religious groups. However, the apparent differences in HIV prevalence rates according to religious affiliation are not statistically significant in any of the three countries included in table 7.

To identify the relative importance of the many HIV risk factors and applicable ranges, population-based studies of a representative sample of about 1,000 men and 1,000 women were undertaken in four cities with sharp differences in HIV prevalence rates. Several

Table 7. HIV prevalence among men by circumcision status in Burkina Faso, Ghana and Kenya, 2003

	Burkina Faso		Ghana		Kenya	
	Circum-cised	Uncircum-cised	Circum-cised	Uncircum-cised	Circum-cised	Uncircum-cised
Percentage of all men	88.5	11.5	95.3	4.7	83.4	16.6
Percentage of men aged 15-19 years	84.0	16.0	95.1	4.9	70.3	29.7
Percentage HIV-positive (total no.)	1.8 (3 034)	2.9 (395)	1.6 (4 258)	1.4 (210)	3.0 (2 538)	12.6 (505)
Chi-square/statistical significance	2.2380/not significant		0.0511/not significant		88.5793/p = <0.0001	
Religion Percentage (and number) HIV-positive						
Roman Catholic	1.3 (718)	4.1 (185)	1.2 (607)	— (39)	2.6 (670)	14.2 (150)
Protestant/other Christian	3.9 (121)	* (23)	1.8 (2 435)	>0.09 (94)	3.0 (1 510)	12.7 (326)
Muslim	1.8 (1 899)	— (40)	1.3 (819)	* (17)	2.9 (188)	* (—)
No religion/traditional	2.9 (274)	1.5 (141)	2.2 (395)	2.8 (94)	5.6 (166)	(3.6)** (26)
Chi-square/statistical significance	5.6370/not significant		2.4411/not significant		4.1265/not significant	

Sources: National Demographic and Health Surveys for Burkina Faso, Ghana and Kenya (2003), available at http://www.measuredhs.com/.

* Figure is unavailable or nil/negligible.

** The use of parentheses here denotes reference to a relatively small number.

hypotheses were proposed to test the association of specific factors, or combinations thereof, with the increased risk of HIV. These factors included, inter alia, differences in the numbers of sexual partners and frequency of intercourse, the time elapsed since HIV had been introduced into the country, and whether a state of equilibrium had been reached. Research was undertaken to determine whether there were differences in susceptibility to infection based on the presence or absence of traditional practices such as circumcision or biological factors such as concomitant infections. The strongest associations were between the prevalence of HIV, herpes simplex virus type 2 (HSV-2) infection, and male circumcision.[230] The researchers concluded that the "efficiency of HIV transmission as mediated by biological factors outweigh[ed] differences in sexual behaviour in explaining the variation in rate of spread of HIV between the four cities."[230] Findings from a separate study indicate that in Tanzania, at least, recognition of the protective effect of circumcision appears to have increased

the popularity of this practice among traditionally non-circumcising groups.[231]

8.3.2 Female excision

Despite periodic references to potential adverse consequences, there is a dearth of research on the relationship between HIV infection and the practice of excision, more commonly known as female genital mutilation.[232] The different forms of excision range from the slight cutting of the clitoris with no removal of flesh to the complete removal of the labia minora and the sewing of the opposing sides closed; the latter is referred to as infibulation. An excision module has been developed for the DHS and included in 11 national surveys. A perusal of the country reports on excision reveals that the prevalence of the different forms, their distribution among different ethnic groups, and the age at which and circumstances under which the procedure is performed are highly variable. This fact, coupled with the lack of data on HIV prevalence for the surveyed population, underlines the difficulty in undertaking a meaningful comparative analysis for testing the association of excision with HIV risk.

Until more specific studies are undertaken, it is difficult to draw any conclusions beyond the hypothesis that the more severe forms of excision are likely to increase the risk of a female acquiring HIV if her partner is infected. Even if excision is documented and recognized as a risk, remedial action is unlikely, as the procedure carries significance within a larger cultural context that often includes the stigmatization of those who are not circumcised, the practice of levirate, and other, similar beliefs and traditions that deprive women of their rights and participation in family decision-making.[233]

8.4 Illness, death and funerals

Traditional African health-care approaches reflect the centrality of the family and clan. Family members with special gifts not only provide herbal treatments, but also attend to physiological, psychological, spiritual and case management needs.[32, 234] "Among the more traditional African societies of the past and still now in modern times, ... families recognize two causes of illnesses: the immediate or natural cause, often easily understood, and the ultimate or supernatural cause, with the latter necessitating divination. When AIDS appeared in the 1980s and presented a plethora of unusual symptoms, the natural response of families was to label it as a supernatural event and to solicit the help of both the herbal and the divination specialists. Their services continue to be sought."[32] Belief in such systems is not necessarily harmful and may at times be beneficial. A study in Zimbabwe assessed the impact of traditional medicine (phytotherapy) on the quality of life of persons living with HIV and on the progression of the disease over a period of two years. Of the 105 subjects, 79 per cent relied on phytotherapy and 21 per cent on conventional medical care. The type of treatment received was significantly correlated with spiritual domains. The data supported the role of phytotherapy in improving the quality of life of individuals infected with HIV-1, though its pharmacological basis was unknown.[235]

African tradition demands a great show of respect for the dead and specifies the duration of the funeral ceremony and related activities. During this time the bereaved family must bear the expense of feeding the multitude of family and friends coming to offer moral support and gathering to ensure that the deceased is given a respectful farewell.[167]

In rural areas in the past, burials, last funeral rites, and mourning for the dead lasted long periods and incorporated a number of established traditions. While African funeral practices vary, it is not uncommon for the body to be brought home for washing and viewing. Prior to the AIDS epidemic, arrangements were typically made for an elaborate graveside ceremony, followed by a large meal for the mourners and "a weeklong period of mourning in which friends and relatives [slept] in the widow's room and around the house".[186] Neither families nor communities can sustain these

practices. The almost daily deaths are no longer mourned by all the residents of the village, who in earlier times customarily showed respect for the dead by not working in their gardens or fields for several days.[186] If this traditional practice were strictly followed, some villages would spend months without working the farms and hence have nothing to harvest, which would be disastrous. Instead, close relatives of the deceased and those involved in the burial arrangements are the only ones who do not work in the fields. Even for close relatives, the period of mourning before and after burial is now 2-3 days instead of 1-2 weeks.[61]

Burials and funeral rites have changed as well (see box 6). In some rural areas of Zimbabwe a traditional burial would involve the interred man being sat up, wrapped in a cowskin, deep beneath the dung of his cattle kraal, while a woman would be buried next to her granary.[186] Among the Baganda of Uganda, mourners would bring a cloth made from the pounded bark of the mutuba tree to help wrap the body. Because there are not enough artisans to produce the quantities of cloth now needed, the costs have risen tenfold since pre-epidemic times.[186]

Burial societies, common in some areas and only recently introduced in others to cover the enormous burial costs imposed on the family, are becoming widespread, as are the "growth" enterprises of coffin-making and funeral homes. Member families make monthly payments that are expected to cover the costs of a dignified burial, including flowers, generous meals for the mourners and, at times, transportation for the deceased member(s) of the family. With the soaring death rates in some areas, even the burial societies are changing, limiting the definitions of family members covered and requiring a waiting period of several months before the first family member is covered.[61, 186]

Widow inheritance

Widow inheritance, or levirate, has long been a tradition in many societies in Uganda and elsewhere in Africa.[183, 236] It is a means by which the support of a surviving wife (or wives) and children is assured, and is also associated with sexual cleansing rituals (see box 7). The successor to a deceased married man inherits the latter's wife or wives so that they will continue producing children for the clan, and he looks after all the children as his. The major advantage of the custom is that it ensures the care of orphans. The apparently rapid decline in widow inheritance in recent times may therefore have serious consequences for orphan care.[236] "Unfortunately, because of the fear of HIV infection, no man can risk marrying widows even if they are HIV-negative. This has meant that at present no relative of the deceased is solely and culturally obliged to look after the orphans and the widows. The suffering of the widows, widowers and orphans has therefore increased through the change of the custom."[183]

In many traditional societies, men who die of AIDS leave behind widows who are often infected with HIV and may have no legal rights to land or property owing to customary inheritance laws or difficulties in enforcing existing remedial legislation after their husbands' death. Impoverishment may force them to send some of their children away, engage in occasional sex for money, or earn a living as sex workers.[237]

Box 6. Changing funeral practices in the era of HIV/AIDS

"The whole idea of burial associations is alien to the culture of Ugandans. In the past, death was feared, unexpected even by the sick and never planned for. Anyone who tried to plan for their own death or that of relatives or friends was referred to as *enkunguzi* (prophet of doom) and never tolerated by the society. The formation of burial associations is therefore a reflection of the realities of the AIDS epidemic and a mechanism to cope with it. It is also evident that the Uganda community is fully aware of the epidemic."

"The last funeral rites have also undergone major changes. In the past, it took a long time to prepare the last rites. Several months after the burial in Buganda, many relatives and friends would arrive at the home of the deceased several days in advance to prepare for the ceremony. Sexual intercourse with non-relatives attending the rites was encouraged by custom to ensure replacement of the dead. In the face of the AIDS epidemic, all this has changed. Funeral rites take place soon after burial for short periods and are attended by the close relatives of the bereaved family. The sexual orgies are disappearing and are discouraged by the elders."

Source: Excerpts from J. Mukiza-Gapere and J.P.M. Ntozi, "Impact of AIDS on the family and mortality in Uganda" *Health Transition Review* vol. 5 supplement (1995) pp. 201-208

Box 7. Alternative sexual cleansing rituals in the era of HIV/AIDS

"Since sexual cleansing (*kusalazya*) and the intertwined ritual of levirate marriage or widow and widower inheritance (*kunjilila mung'anda*) have come to be implicated in the transmission of HIV/AIDS, alternative rituals to sexual cleansing have emerged. Using both quantitative and qualitative data obtained from Zambia in the second half of 1998, [a] study reveals that the alternative rituals to sexual cleansing include sliding over a half-naked person (*kucuta*) or over an animal (*kucuta ng'ombe* or cow-jumping); [the] use of herbs and roots (*misamu*); [and] cleansing by a married couple. Concoctions or other rituals that were otherwise considered 'alien' in [the] Southern Province, such as [the] cutting of hair (*kugela masusu*) and application of some powder (*kunanika busu*), have also been adopted." The study on which this information is based addresses "various aspects of these alternative practices: who performs them and how; whether the processes are connected to polygyny (*maali*), levirate marriage (*kunjilila mung'anda*), and grabbing or inheriting property (*kukona*); and whether these practices are also risk factors in the spread of HIV/AIDS".

Source: J.R. Malungo, "Sexual cleansing (Kusalazya) and levirate marriage (Kunjilila mung'anda) in the era of AIDS: changes in perceptions and practices in Zambia", *Social Science and Medicine*, vol. 53, No. 3 (August 2001), pp. 371-382.

CHAPTER 9
FAMILY-RELEVANT SECTORAL CONSEQUENCES OF THE HIV /AIDS EPIDEMICS

Capital is the force that raises the productivity of labor and creates the wealth of nations.
—Hernando de Soto, *The Mystery of Capital*

9.1 The economic context of sub-Saharan Africa

While the accumulation of wealth may be among the goals of families, the top priority for families in traditional societies may very well be a sense of security and well-being. Wealth, which in the present context represents an element of the broader concept of family capital, translates into the macroeconomic concept of capital.[238] Historically, traditional societies in sub-Saharan Africa had systems of building and utilizing the "potential energy" of family capital through the relationship component, and wealth was measured by local criteria (for example, in terms of animals or agricultural output). In some settings this was sufficient to create surplus capital, specialization and urban centres. Change came rapidly with colonization and later with independence. During the colonial era political demands for the colonies to cover their own administrative costs led to increased trade, the exploitation of mineral wealth, and the imposition of local taxes. "Methods of rule which imposed the need for money began to undermine traditional economies of subsistence where money had little or no place."[239]

In pursuit of wealth and to ensure the availability of a cheap labour force, South Africa passed the Glen Grey Act in 1894, requiring African men to pay an annual "labour tax" of ten shillings "unless they could prove that during three months of each year they had been in service or in employment beyond the borders of the district".[239] Payments had to be made in cash, not in kind. The system of cash taxation was imposed on village farmers and, with the addition of restrictions on access to and ownership of land by Africans, became the model in other territories.[239] The mining industry, the nascent manufacturing sector, and the large-scale white-owned farms and plantations thus secured a steady source of labour. Cash economies and a pattern of circulatory migration between towns and the countryside emerged in many sub-Saharan locales.[239, 240] In some settings men could migrate with their families and often set up homes in the peri-urban shantytowns outside the jurisdiction of local urban authorities.[240] In many areas, however, particularly those in which a large, concentrated, long-term workforce was required, labour migration was restricted to the workers, who were accommodated in barracks-like dormitories. Labour migration in South Africa, including that involving workers from neighbouring countries, has long been recognized as a practice that undermines the normal social institutions and disrupts family life.[241]

Increasing numbers of women have also been compelled to migrate; their movement to urban centres as a consequence of a barren marriage, the break-up of a child marriage, or trafficking, or in connection with poverty (including the need to pay school fees or to satisfy other economic demands placed on young females), has left them open to sexual exploitation and prostitution. [214, 217, 242, 243]

Cultural and colonial history, the labour situation, and land, natural resources and geography have shaped the present-day national economies in sub-Saharan Africa. These factors have also influenced the patterns of population and labour migration and movement, and

developments in this context appear to have contributed to the risk of families being newly affected by HIV/AIDS. To varying degrees, social, economic and political developments will continue to affect and be affected by the diverse national and regional patterns of the HIV/AIDS epidemics in Africa and elsewhere. These developments are manifested in specific sectors, and their impact may be measured using a series of human and economic development indicators as well as sector-specific indicators. The manner in which families relate to or operate within the relevant sectors affects their accumulation of family capital and their vulnerability to the effects of HIV/AIDS.

Failing to acknowledge the differences and variations in these patterns makes it impossible to gain a more nuanced understanding of the three HIV/AIDS epidemics, their impact on families, and the most effective policy options based on time constraints (the level of urgency) and the availability of national and international resources.

Even in subsistence-farming and other settings characterized by limited economic development, family capital is accumulated and protected largely through public institutions and sectors, and through the interaction of families with other sectors and institutions comprising the larger economy. Factors contributing to family capital include the knowledge and skills acquired through education and technical support from agricultural extension workers, the availability of health-care and services, microcredit opportunities, employment- or community-based insurance, and earnings from wages or from products sold in a market economy.

In sub-Saharan Africa, contrary to the popular rhetoric, it is neither the poorest countries nor the poorest people who are at the greatest risk of being affected by HIV/AIDS. Comparative analyses among sub-Saharan African countries reveal a number of correlations of potential social policy importance. Notably, the findings indicate that the annual rates at which families are newly affected by HIV/AIDS vary by as much as 30-fold (see table 1), and that five of the six countries categorized as middle-income have annual incidence rates of at least 10 per thousand unaffected families, while only 5 of the 28 low-income countries have such high annual rates (see table 8).

A series of multiple regression analyses have been used to test the correlation of economic indicators such as the human poverty index (HPI), gross national income (GNI) per capita adjusted for purchasing power parity (PPP), and the contributions of agriculture, industry and services to gross domestic product (GDP) with several of the indicators of children's living arrangements, and with adult HIV prevalence rates and the rates at which families are newly affected by HIV/AIDS. The share of GDP derived from industry and services* is an indication of (a) the productive capacity of the manufacturing, mining and energy extraction sectors, and of some services sectors, which have traditionally drawn individuals and families from dispersed rural areas to towns and cities, and (b) the extent of participation in occupations and leisure activities associated with mobility and increased HIV/AIDS risks.

Among the 34 sub-Saharan African countries there is no statistically significant correlation of the HPI with either the living arrangements in which the children reside with their mothers while the father is alive, but absent or with the incidence of families newly affected by HIV/AIDS.† However, the percentage of people living on less than one US dollar per day is negatively correlated with the absentee father indicator. (see annex III, table 13) The latter

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* The industry sector includes mining, manufacturing, construction, electricity, water and gas; and the services sector includes wholesale and retail trade (including hotels and restaurants), transport, and government, financial, professional and personal services such as education, health-care and real estate services; information accessed from *World Bank Data & Statistics* http://www.worldbank.org/data/countrydata/aag.htm..

† Among 34 countries the Adjusted R-squared = 0.03, and the significance of $F = 0.164$.

Table 8. Annual rates at which families are newly affected by HIV/AIDS, by income group, 34 sub-Saharan African countries, 2001-2003

	Annual incidence rate (per 1,000) of families newly affected by HIV/AIDS					
Income group	< 0	1.0 to 2.9	3.0 to 5.9	6.0 to 9.9	10.0 and >	Total
Upper-middle					3	3
Lower-middle			1		2	3
Low-income	2	7	7	7	5	28

Source (for income groups): World Bank, *World Development Indicators* database (Washington, D.C., July 2004).

living arrangement indicator, as well as that in which children reside with neither parent but both parents are alive are significantly correlated with per capita GNI-PPP, which account for 69 and 62 per cent of the variation in the respective living arrangements. The addition of the percentage of children attending school to the regression adds significantly to account for nearly 80 per cent of the variation in the living arrangements in which the father is absent. The two economic indicators—GNI-PPP and GDP—are strongly correlated with the HIV/AIDS indicators,* such that the better the economic circumstances and the greater the share of industry and services in GDP, the higher the prevalence of HIV infection among adults and the higher the rate at which families are newly affected by HIV/AIDS (see annex III, table 14). The addition of one of the residential arrangements in which children live with the mother but have an absentee father or in which both parents are absent and the children reside with a foster family increases the statistical significance of the analysis, accounting for 40 to 45 per cent of the variation in the annual rate at which families are newly affected by HIV/AIDS (see annex III, table 15). The addition of both or of other living arrangements produces no further explanation of the variation or increase in the statistical significance of the regression model.

Virtually all studies covering the epidemics since their onset in various countries have indicated that individuals with greater mobility and higher levels of education and income are among the first to experience HIV- and AIDS-related mortality. As the epidemic "matures", it is not uncommon to find a net decrease in the numbers of teachers, health professionals and agricultural extension workers in the affected areas. In sub-Saharan Africa, especially early in the epidemic, men and women with higher levels of education and income were more likely than others to contract HIV.[244] A survey of 11 studies carried out in Malawi, Rwanda, Tanzania, Uganda and Zaire in the late 1980s and early 1990s revealed that HIV infection was positively correlated with socio-economic status as determined by schooling, income and occupation. The argument is that men with higher levels of education and income find it easier to attract and support additional commercial and casual sexual partners,† and that

* The share of industry and services in GDP is associated with over 25 per cent and the PPP-GNI per capita with 47 per cent of the variation in the incidence rate of families newly affected by HIV/AIDS among 32 sub-Saharan African countries. ($p<0.002$ and <0.0001 respectively).

† In Kenya, J.M. Deheneffe, M. Caraël and A. Noumbissi (as cited by T. Yamano, T.S. Jayne and M. McNeil in "Measuring the impacts of adult death on rural households in Kenya" [Washington, D.C., World Bank, April 2002], p. 25) identified a positive relationship between education and the probability of having at least one non-regular sexual partnership (any sexual relationship of less than one year) in the past 12 months among 1,083 men and 1,482 women aged 15 to 49 years in 1990. D. Filmer (as cited in the same publication), also detected a positive

men (and women) with a better education and income are likely to travel more.* A study from Tanzania shows that the probability of dying from AIDS increases with educational level until the seventh year of schooling, while the probability of dying from other causes declines after three years of schooling.[245]

In all settings the HIV epidemic follows the trade routes and those who are mobile. In a study from Uganda, rates of HIV infection among individuals aged 13 years and over were almost 35 per cent in the trading centres, 21 per cent in the trading villages, and 11 per cent in the rural/agrarian villages. In the trading centres, 47 per cent of households had at least one resident HIV-infected adult; in the villages the rate was just over 20 per cent. HIV prevalence was higher among heads of households than among the general adult population, with respective rates of 43, 27 and 13 per cent in the trading centres, trading villages and rural villages.[177]

Notwithstanding the analysis and references provided above, the association between income/wealth and HIV infection is only partially confirmed in the household-level analysis of the HIV-prevalence subsample in the DHS studies for Burkina Faso, Ghana and Kenya (see table 9). In Kenya there is a statistically significant, higher-than-expected proportion of women and men in the top quintile for wealth who are HIV-positive. This is true only for the women in Burkina Faso; the trend is evident but not statistically significant among the men. While the prevalence of HIV infection is substantially higher among the middle sixtieth percentile of women in Ghana, it is at a lower order of significance; among the men in the corresponding percentile range, the association between wealth and HIV prevalence is not significant. A study from Côte d'Ivoire illustrates the difficulties and complexities associated with undertaking and interpreting the results of studies relating indicators of poverty, income and education to the risks of adult death—whether from AIDS or other causes—in family households (see table 10).[246] The study, effectively based on a case-control design though not so thoroughly analysed, compared contributing factors and outcomes in 600 households, 400 of which had experienced an AIDS-related or non-AIDS-related adult death in the previous 24 months, and 200 of which had experienced no adult deaths in the same period. The research was restricted to three urban areas. The results were presented only in a descriptive format; however, an odds-ratio analysis applied to the data revealed that, other than a 10 per cent lower per capita income in the AIDS-related-death group, there was little difference between the household groups in terms of characteristics that would be seen as reflecting differences in either family capital or poverty levels (including the education level of the head of household, the

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relationship between education and the probability of having a non-regular partner in Kenya, based on DHS data for 1993. However, the positive relationship was statistically significant only among women, not among men. Filmer also found a positive relationship between education and the probability of using a condom with a non-regular partner. (For original source references see J.M. Deheneffe, M. Caraël and A. Noumbissi, "Socioeconomic determinants of sexual behaviour and condom use", in *Confronting AIDS: Evidence from the Developing World*, M. Ainsworth, L. Fransen and M. Over, eds. [Brussels, European Commission, 1998]; and D. Filmer, "The socioeconomic correlates of sexual behaviour: a summary of results from an analysis of DHS data", included in the same publication).

* As information on HIV/AIDS is more widely disseminated, men and women with higher levels of education and income may start protecting themselves better than those with lower levels of education and income. A recent study of four African cities found a positive correlation between education and condom use (see E. Lagarde and others, "Condom use and its association with HIV/sexually transmitted diseases in four urban communities of sub-Saharan Africa", *AIDS*, vol. 15, No. 4, supplement [August 2001], pp. S71-S78).

Table 9. Rates of HIV seropositivity by sex and wealth quintile from household surveys in Burkina Faso, Ghana and Kenya, 2003

		Population sample	Number HIV-positive	Percentage HIV-positive by wealth quintile			*p* value
				Lower 20%	Middle 60%	Upper 20%	
Burkina Faso	Women	4 086	75	0.9	1.4	3.4	<0.0001
	Men	3 065	58	1.4	1.6	2.7	Not significant
Ghana	Women	5 097	137	1.4	3.2	2.4	<0.025
	Men	4 046	58	1.4	1.6	1.1	Not significant
Kenya	Women	3 151	274	3.9	8.5	12.2	<0.0001
	Men	2 849	130	3.4	3.6	7.3	<0.0001

Source: Demographic and Health Surveys for Burkina Faso, Ghana and Kenya (2003), available at http://www.measuredhs.com/.

ownership of the home and household durable goods, and religious or political affiliation).

Among the outcome variables, the apparent differences between families that had experienced an AIDS-related adult death and those that had experienced a non-AIDS-related adult death, and the association between those families and the prevalence of double orphans and of child deaths, were not statistically significant. However, children in a family affected by an adult AIDS-related death were less likely to obtain the necessary health care than were those in families with a non-AIDS-associated death or without an adult death in the preceding two years. Significant differences in the risk of a child being withdrawn from school were only apparent when the group of families experiencing an AIDS-related adult death in the previous two years were compared with those that had not experienced an adult death during the same period (odds ratio = 1.34; 95 per cent confidence interval, 1.03-1.74).

A detailed breakdown of these data reveals that the observed results are not compatible with a "simple" explanation linking poverty and AIDS, but quite the opposite: only in the higher-income group is there an increased risk of double orphanhood among those families that have endured an AIDS-related adult death in comparison with families that have experienced a non-AIDS-related adult death (odds ratio = 2.23; 95 per cent confidence interval, 1.02-4.84); and among those families in which an adult AIDS-related death has occurred, those with higher incomes face more than twice the risk of those with low incomes of having double orphans (odds ratio = 2.33; 95 per cent confidence interval, 1.27-4.27). Since the prevalence of double orphans associated with AIDS is known to increase with the duration of the HIV/AIDS epidemic in different countries and groups, it is not unreasonable to assume that those with high incomes were among the first to become infected in the urban settings of Côte d'Ivoire.

9.2 The impact of the HIV/AIDS epidemics on household resources and their allocation in families

Though there is some variation among countries in sub-Saharan Africa, HIV/AIDS should primarily be seen not as a consequence of poverty, but as impoverishing those belonging to the nascent middle and professional classes, which have constituted the driving force behind economic and social development in the subcontinent, and ultimately as impoverishing the countries in which they live. In families forced to deal with AIDS, resources quickly

Table 10. Characteristics of households, child health and education, by household adult death experience, Côte d'Ivoire, 2001

	Households that experienced an AIDS-related death (HAD)	Households that experienced death from other causes (HOC)	Households in which no deaths occurred (HND)	Odds ratio: (a) HAD/HOC (b) HAD/HND (95 per cent confidence interval)
Urban households interviewed	202	196	196	-
Total number of household members	1 592	1 662	1 527	-
Indicators of family capital				
Average per capita income (US dollars)	US$ 502	US$ 561	US$ 593	-
Illiteracy among adults (%)	27.6	24.7	22.1	(a) not significant; (b) not significant
Households that do not own the houses in which they live (%)	47.0	38.8	54.1	(a) not significant; (b) not significant
Households without any durable consumer goods (%)	14.9	12.2	11.7	(a) not significant; (b) not significant
Heads of household without any political or religious affiliation (%)	36.3	32.6	37.0	(a) not significant; (b) not significant
Family structures, health, health care and education				
Double orphans (%)	10.9	4.1	2.1	(a) not significant; (b) not significant
Paternal orphans (%)	32.3	35.5	7.7	(a) not significant; (b) = 1.81 (1.32-2.50)
Maternal orphans (%)	11.5	10.1	3.1	(a) not significant; (b) not significant
Household children who died of all causes (%)	2.5	0.7	0.1	(a) not significant; (b) not significant
Household children who were sick (%)	46.4	40.7	39.1	(a) not significant; (b) not significant
Household children without access to health centres despite the need for services (%)	48.7	26.8	29.5	(a) = 1.56 (1.26-1.93); (b) = 1.44 (1.16-1.79)
Household children withdrawn from school (%)	27.7	18.5	16.0	(a) not significant; (b) = 1.34 (1.03-1.74)

Source: Adapted from J. Pégatiénan and D.A. Blibolo, "HIV/AIDS, lagging policy response and impact on children: the case of Côte d'Ivoire", in *AIDS, Public Policy and Child Well-Being* (Florence, UNICEF-Innocenti Child Development Centre, June 2002), chapter 5; also available at http://hivaidsclearinghouse.unesco.org/.

evaporate. In the later years of a family member's HIV infection, and as AIDS-related symptoms become more apparent, the individual's productivity and income decline as absences from work and expenditures increase; this is true in both developed and developing countries.[247, 248, 249] In an analysis of participants in an ongoing cohort study from Switzerland, the mean annual productivity loss per patient was estimated at over US$ 15,000.[247] A group of tea estate workers in Kenya who were HIV-positive and subsequently medically retired because of AIDS were compared with a matched group of uninfected workers assigned the same tasks in the same fields. The members of the HIV/AIDS group earned 16 to 17 per cent less, were assigned less strenuous tasks, and were more frequently absent on sick and annual leave in the two years before medical retirement.[250]

The family-relevant sectoral consequences of HIV/AIDS are mediated by the manner in and extent to which each of the three epidemics affects family and social capital. These effects are. neither isolated nor simply accumulative, but relate to the nature, structure and functioning of each sector in particular social and cultural contexts (see table 11). It is within this framework that the interrelated sectors of agriculture, mining, and education are examined in this chapter, in connection with the related role of migration. Strategies for reducing vulnerability to HIV include measures designed to address the underlying factors that create an overall climate in which risk-taking behaviours are encouraged, sustained, and prove difficult to change (see table 11 and box 8). Addressing HIV vulnerability entails improving the living, working, and other socio-economic conditions and circumstances of rural men, women and children in order to ensure that during periods of stress, household coping strategies and social safety net mechanisms are resilient enough to withstand the crisis. Essentially, HIV/AIDS vulnerability reduction strategies do not address the specific high-risk behaviours but the underlying factors responsible for such behaviours, taking into account the interrelationships between these factors and HIV/AIDS.[40]

Contributing to the family-relevant sectoral impact is the nature and extent of the stigma surrounding HIV/AIDS in a particular setting, and the translation of that stigma into legislative and/or community-level discrimination, which reinforce each other and may not always be easily delineated (see table 12). [106]

9.3 Migration: economic necessity and family vulnerability

Migration and the variable circumstances surrounding population movement and disruption, such as severe poverty and armed conflict, may potentially place family members at increased risk of HIV infection.[14] The expectation of better economic opportunities is a major motivation for migration from rural to urban areas and between countries. A person who decides to migrate may anticipate that the move will be either temporary or permanent, and when the individual has strong family bonds, migration may occur in stages. In the context of expanding labour markets, migration is frequently age- and gender-specific according to the human resource needs in such areas as mining, agriculture, forestry, textile production, electronics manufacturing, and domestic service. Immigration policies frequently accentuate the sex-based bias by not permitting the concurrent or subsequent migration of the families of "guest workers".[251] Regardless of whether the migrants are individuals or families, their remittances constitute a major source of economic support for those family members that remain behind, and contribute to the community of origin and the national economy. Remittances also provide an important buffer that effectively protects and enhances family capital by reinforcing family bonds and by augmenting family wealth.

Labour migration and mining employment opportunities in South Africa have been critical to the welfare and well-being of families in neighbouring countries. For example, 20 years ago only 2 per cent of the land in Lesotho was

Table 11. Factors affecting the family-relevant sectoral impact of the HIV/AIDS epidemics

Epidemic	The family-relevant sectoral impact is a function of:
HIV epidemic	▪ Whether the vulnerabilities of families have been addressed through protective policies in relation to the following: • Migration for wage labour; • Health education and services for school-age young people; • Sexual harassment, exploitation and/or other factors increasing the vulnerability of young and adolescent girls in school, and of women in places of employment or the community; • Harmful traditional practices; ▪ The development and implementation of policies to eliminate child labour and the commercial sexual exploitation of children; ▪ The availability of and accessibility to reproductive health services and non-traditional outlets for such services, including voluntary counselling and testing, education, advocacy and interventions for HIV prevention (for both individuals and couples).
AIDS epidemic	▪ AIDS-specific and AIDS-related illness mortality rates (both age- and sex-specific rates and cumulative totals); ▪ The epidemiological pattern in terms of time, place, and infected persons; ▪ The changing population structure; ▪ The nature of the economy/sector in terms of whether it is labour- or capital-intensive, is knowledge- or skill-dependent, or has a high degree of labour mobility, migration or movement of goods; ▪ The extent to which those who engage in productive/income-generating labour reside with or away from their families; ▪ The accessibility and affordability of treatment for HIV/AIDS and AIDS-related illnesses.
Epidemic of fear	▪ Political will and recognition by national authorities that responding to HIV/AIDS is a priority for economic and social development; ▪ Whether national and institutional policies have been established, the focus and nature of those policies, and the degree of consistency between national policies and those of all relevant institutions; ▪ The availability, distribution and effectiveness of accurate information on HIV/AIDS; ▪ The cultural basis of stigmatization and the contexts in which discrimination is manifested, either at the community level or through legal/administrative action; ▪ The extent to which national authorities and relevant institutions have addressed the issues of stigmatization and discrimination both at the community level and by legislative or administrative action; ▪ The effects of knowledge, culture, stigma and discrimination and the responses of society in the different realms.

Table 12. Contexts of HIV/AIDS discrimination and its impact on the family

Contexts of discrimination	Examples of impact
Family/immediate community	▪ Isolation of both infected and affected individuals owing to fears of casual contact; ▪ Restrictions on participation in local events; ▪ Refusal to allow affected children in local schools; ▪ Lack of support for bereaved family members, including orphans.
Workplace	▪ Mandatory testing before hiring; refusal to offer employment; ▪ Involuntary periodic testing; dismissal on the grounds of HIV seropositivity; ▪ Violations of confidentiality; ▪ Refusal to work with infected colleagues out of fear of contagion.
Health sector	▪ Refusal to treat infected individuals; ▪ Violations of confidentiality; ▪ The provision of care in certain types of establishments (such as STD clinics) that further stigmatize the client; ▪ Advice given or pressure applied for an HIV-positive person to undergo treatment that would not be recommended for others (including abortion and sterilization).
Religion	▪ Denial of traditional rituals (including changes in funeral practices and more restricted marriage opportunities for HIV/AIDS-affected families); ▪ Restrictions on participation in religious activities.
Media	▪ Demonization by public health campaigns of specific "transmitters" such as sex workers, reinforcing divisions between "guilty" and "innocent" persons living with HIV/AIDS; ▪ Depiction of HIV/AIDS as death, perpetuating fear and anxiety rather than normalization; ▪ The reinforcement of stereotypical gender roles that perpetuate women's vulnerability to sexual coercion and HIV infection.

Source: J.R. Busza, "Promoting the positive: responses to stigma and discrimination in Southeast Asia" *AIDS Care*, vol. 13, No. 4 (August 2001), p. 441, as adapted from A. Malcolm and others, "HIV-related stigma and discrimination: its forms and contents", *Critical Public Health*, vol. 8, No. 4 (1998), p. 347.

arable, and 60 per cent of the adult males between 20 and 44 years of age were employed in the mines of South Africa.[252] Around 70 per cent of rural households had at least one migrant member, with remittances constituting two thirds of the household income on average. Around the time when mining was starting to become less labour intensive and technological and agricultural development strategies were emerging, HIV/AIDS hit the country with a vengeance. The present analysis indicates that 43 per cent of families in Lesotho are affected by HIV/AIDS. The 1.85 per cent annual incidence rate, reflecting the share of families newly affected each year, is the highest in Africa and probably the world. The net annual rate of decline in HIV-free families is 1.6 per cent.

It has long been known that HIV prevalence and migration status are strongly correlated in different regions of Africa.[253, 254] In a South African study migrants and non-migrants from the same region were compared on the basis of HIV status, various social and demographic factors, and risk behaviours.[255] HIV prevalence was 25.7 per cent among migrant men and 12.7 per cent among non-migrant men; however, prevalence rates were no higher for the women partners of migrants than for those of non-migrants (odds ratio = 2.4; 95 per cent confidence interval, 1.2-5.4). Temporary or intermittent non-resident migrants, often described as either seasonal or circular migrants, are among those most vulnerable to HIV/AIDS and serve as a major source of infection within their families and communities of origin.[256] These migrants are often at the age of peak sexual activity and, in moving to urban settings or other countries, find themselves outside the realm of traditional values and social control imposed by their indigenous rural or national culture. Whether out of loneliness or in response to peer pressure in the largely male communities involved in mining, forestry and some types of large-scale urban manufacturing, men engage in high-risk sexual activity with sex workers, serial or multiple girlfriends, or casual sex partners, often in connection with alcohol abuse. Women migrants have to deal with sexual harassment, pressure to exchange sexual favours, or rape. The accelerating rates of HIV seropositivity in many rural areas appear to be linked to the circumstances mentioned above, as well as to a combination of other factors, including improvements in the transportation infrastructure (facilitating circular migration over greater distances), wider sexual networking

Box 8. Vulnerability to HIV spread and impact

Vulnerability to the spread of HIV is associated with the following:

- Migration for wage-based employment;
- High alcohol consumption;
- Proximity to transport or trading centres;
- Frequent interactions with market centres;
- The low status and limited economic independence of women;
- Physically damaging sexual practices;
- Widespread exchange of cash or favours for sexual services.

Increased vulnerability to the impact of HIV derives from the following factors:

- Drought;
- Limited crop ranges;
- Marked labour peaks in the agricultural cycle;
- Labour-intensive processes;
- The absence of a tradition of labour exchange between households;
- Existing pressures on the domestic-farm interface;
- Limited substitutability between existing labour-intensive and less labour-demanding crops;
- Already low food surpluses;
- Limited opportunities for off-farm income;
- Insecure land tenure.

Source: Tony Barnett, "Subsistence agriculture", *AIDS Briefs for Sectoral Planners and Managers*, A. Barnett, E. Blas and A. Whiteside, eds. (Geneva, WHO Global Programme on AIDS and UNAIDS, 1996), vols. 4-5, p. 5.

and, in the case of South Africa, the lifting of travel restrictions.[257] Most circular migrants are men. Among the female non-resident family members who migrate, many are driven by poverty into commercial sex work.[14]

During the past three decades various social and economic forces have altered the dynamics of—and intensified the dynamic relationship between—migration, mobility, and sexual behaviour in northern Thailand. New pressures have been created in connection with the following: changes in the economic and demographic structure resulting in rural-urban migration; gender role expectations with regard to contributing to the family household and caring for ageing parents; gender differences in educational and labour opportunities, resulting in female rural-urban migration; and changes in traditional social controls over sexual behaviour. Pathways to mobility include marriage, education and urban employment.[258]

High rates of female urban migration are linked to the different expectations parents have with regard to the filial obligations of daughters and sons. In Thailand, parents have three major responsibilities: providing for and raising their children to adulthood; accumulating wealth for their children to inherit; and encouraging daughters to marry to ensure parental old-age security (a dependency reversal).[259] The tradition of "parental repayment", shared by virtually all segments of society, carries the expectation that children will provide comfort and support to their parents. The concept of *bounkhun*, or practical and moral indebtedness, reflects a sense of obligation and serves as an impetus for women to seek employment opportunities that will allow them to accumulate wealth for the care of their ageing parents.[259] Throughout Thailand, marriage has traditionally been viewed as a woman's primary pathway to social mobility and a means by which she can provide security for her parents as they get older. In contrast, the family role of sons is associated more with maintaining stability—providing local labour or participating in family economic schemes (through involvement in agricultural activities or the trading of family wares, for example). Unlike a daughter, a son is able to repay his *bounkhun* by being ordained as a monk.[258]

More generally, daughters are seen as a principal means of improving the family's economic situation, contributing wages and other income that may ultimately provide educational opportunities for younger siblings. Most non-farm occupational opportunities, including office, factory and service jobs, are urban-based. These options are available only for girls from families with enough resources to invest in formal education—resources beyond the grasp of many villagers in northern Thailand.[258] Poverty may compel young women to seek employment outside their communities; however, their lack of education limits their options, and many eventually end up as sex workers.[258, 260]

While the circumstances outlined in this section are specific to particular settings, they reflect a more general global trend. In sum, the social and economic environment in some areas is inducing certain segments of the population, including young women, to move from the countryside to cities, from the hills to the lowlands, and across national borders. It is important to recognize that while the economic benefits of labour migration are undisputable, such movement may also be associated with increased risks to the health and well-being of the migrants and their families.

9.4 Agriculture and food security

African economies are based on rural subsistence production. Even relatively industrialized countries such as Kenya and Zimbabwe have dominant agricultural sectors providing a livelihood for some 80 per cent of the population. Hence, the local food-population balance is critical. In the past it was predicted with some confidence that Africa's population would increase rapidly for many decades, so agricultural production would need to be greatly expanded. It was suggested that agricultural production in sparsely populated areas could be

improved enormously if long fallow agriculture and pastoralism were replaced with more labour-intensive systems.[261] Now, however, it may be necessary to consider policy options that take into account the decline in population in circumstances in which overall economic viability centres on rural household production.

The detrimental impact HIV/AIDS may have on the productive capacity of rural households has been extensively studied in eastern Africa.* The effects of HIV/AIDS may be considered in connection with various farm production parameters. First, the quality and quantity of household labour are reduced; productivity declines when the HIV-infected person is ill, and the labour supply diminishes with the death of that person. Moreover, there is a high probability that more than one adult per family is infected, given the heterosexual nature of HIV transmission in Africa. A compounding factor is the higher infection rates among women, who account for 70 per cent of the agricultural labour force and 80 per cent of food production. In addition, other household members must devote productive time to caring for the sick, and traditional mourning customs can adversely affect labour availability.[262]

If a household becomes unable to either supply sufficient labour internally or hire temporary workers, the size and composition of crops may gradually be altered, with a shift from cash to subsistence crops occurring in some cases. The key constraint is the unavailability of manpower during periods of peak labour demand, usually during the planting and harvesting seasons. Given the nature of the rural labour market, these are also times when wages and opportunity costs are highest. One response to the labour shortage may be to reduce the area under cultivation. It is likely that livestock production will be less intensive as well, and that the quality of farming will be affected by the curtailment of weeding and pruning activities. A shift to crops that are less labour-intensive will halt vegetable cultivation, resulting in a less varied and less nutritious diet. "Labour-intensive farming systems with a low level of mechanization and agricultural input are particularly vulnerable to the impact of the disease."[262] Some of the effects of the labour shortage in eastern African communities that have experienced the full impact of HIV/AIDS include the following:

- A reduction in the amount of land under cultivation;
- A delay in farming operations such as tillage, planting and weeding;
- A reduction in the ability to control crop pests;
- A decline in crop yields;
- A loss of soil fertility;
- A shift from labour-intensive crops (such as bananas) to less labour-intensive crops (such as cassavas and sweet potatoes);
- A shift from cash-oriented production to subsistence production;
- A reduction in the range of crops per household;
- A decline in livestock production;
- A loss of agricultural knowledge and management skills.[262]

Because circumstances vary, families and communities experience these effects

* The following studies assess the impact of HIV/AIDS on the agricultural production and productivity of rural households: (a) FAO, *The Effects of HIV/AIDS on Farming Systems in Eastern Africa* (Rome, 1995); (b) A. Evans, "A review of the rural labour market in Uganda" (University of Sussex, 1992); (c) T. Barnett and P. Blaikie, "How households, families and communities cope with AIDS", in *AIDS in Africa: Its Present and Future Impact* (London, Belhaven Press, 1992); (d) FAO, "The potential impact of AIDS on agricultural production and consumption in Malawi" (Rome, 1991); (e) S. Gillespie, "Potential impact of AIDS on farming systems: a case study from Rwanda", *Land Use Policy*, vol. 6, No. 4 (October 1989), pp. 301-312; and (f) FAO, "Potential impact of AIDS on food production and consumption, Tabora Region: Tanzania case study" (Rome, 1989).

differently. The results and findings deriving from activities carried out by FAO in eastern Africa "reveal that the impact of HIV/AIDS on agricultural production systems and rural livelihood cannot be generalized, even within one country, and must be disaggregated into spatial and temporal dimensions".[262]

In Kenya, "the death of a household head is associated with [a] 60 per cent reduction in the value of the household's crop production (net of major cash input costs). The gender of the deceased adult affects the type of crop suffering a shortfall, with grain crops being adversely affected in the case of adult female mortality and "cash crops" such as coffee, tea, and sugar being most adversely affected in households incurring the death of a male household head. . . the death of a household head is also associated with a significant reduction in farm equipment, non-farm asset items (e.g., radios, bicycles), and off-farm income."[263] The death of a female adult member is associated with a significant reduction in the number of cattle.[263]

According to a recent report, communal agricultural output in Zimbabwe has fallen by a staggering 50 per cent over the past five years, largely as a result of HIV/AIDS.[40] Maize, cotton and sunflower yields have been particularly affected. Maize production, which amounts to over 4 million tons, has been marked by a 54 per cent decline in harvested quantities and a drop of 61 per cent in marketed output. The total area under cultivation for this crop has been greatly reduced as well. Cotton hectarage has decreased by about 34 per cent and marketed output by 47 per cent, and groundnut and sunflower production have fallen by an average of 40 per cent. Livestock production has also been declining, with losses reportedly higher among AIDS-affected households owing to insufficient care. The sale of draught power is believed to be higher among such families as well.

Clearly, the decline in yields is also linked to factors other than HIV/AIDS, including shortages of labour, draught power, and purchased inputs (such as seed, fertilizer and agrochemicals).[264] However, given the staggering AIDS mortality rates in Zimbabwe, it is certain the pandemic has played a catalytic role in this adverse trend. Slightly more than 50 per cent of all deaths reported in communal agricultural areas are related to HIV/AIDS, with males accounting for 78 per cent of those succumbing to the manifestations of the disease. The wives they leave behind (who are also likely to suffer from increased morbidity) are becoming a key group of agricultural producers.

The net result of the marked decline in crop yields and livestock production is heightened food insecurity. "With increasing HIV infections and subsequent deaths, the threat to national food security cannot be overemphasized, and declines to marketed output will adversely affect the agro-industries, which will experience cuts in raw materials supply and force them to operate below full capacity."[264] Malnutrition, as measured by stunting in children, is an expected consequence of long-term food insecurity. However, a preliminary regression analysis of data from 27 districts in Malawi[265] and 10 provinces in Mozambique failed to demonstrate any association between adult HIV prevalence and the prevalence of stunting in children. It is quite probable that the impact of the high incidence and interactions of other factors affecting the nutritional status of children (such as malaria, diarrhoeal and acute respiratory diseases, and micronutrient deficiencies) is of such magnitude that the addition of HIV/AIDS-related consequences to the scenario has only a marginal impact, if any, on stunting. The findings of the Côte d'Ivoire studies indicated that there were no significant differences in the incidence rates of illness among children in any of the three categories of families studied (those that had experienced an AIDS-related adult death, those that had experienced an adult death from other causes, and those in which there had been no adult death during the period under review).[246]

It is worth mentioning that individuals involved in the fishing industry are vulnerable as well. "Artisanal fishing communities are at increased risk of contracting HIV due to the

socio-economic dynamics of their trade, including mobility, prolonged periods of separation from their families, and disposable cash incomes."[266]

"In macroeconomic terms, countries most affected by HIV are also those most heavily reliant on agriculture, and particularly on agricultural exports for foreign exchange needed to pay for raw materials and essential imports for development. Thus, the impact of HIV/AIDS on rural communities and on rural economies in general (and not just agriculture) is of critical significance to such countries. However, as it is not always visible or measurable with macroeconomic indicators (such as gross domestic product or per capita income), it is often all too easily dismissed as a minor factor in development policies and programmes, particularly insofar as rural development is concerned."[40]

9.5 Education

The education of children is universally recognized as a major motivating factor influencing intrafamily decision-making and the allocation of household resources. It engenders a sense of social esteem for the family and represents one of the most critical investments for many forms of family capital. Regrettably, a persistent gender bias in education in many societies denies women and girls an equal opportunity to realize their potential and the means to contribute more fully to the accumulation of family capital and to their families' health and well-being.

The functions of the family and its ability to accumulate family capital through education can be directly or indirectly affected by HIV/AIDS-induced changes in the following:

- The demand for education;
- The supply of education;
- The availability of resources for education;
- The potential clientele for education;
- The process of education;
- The content of education;
- The role of education;
- The organization of schools;
- The planning and management of the education system;
- Donor support for education.[267]

The main family-relevant effects of HIV/AIDS in the realm of education operate at three levels:

- Declining school attendance among children from families affected by HIV/AIDS;
- Declining numbers of teachers as a result of death from HIV/AIDS, which affects virtually all families;
- The increased risk of acquiring HIV/AIDS from sexual exploitation, particularly for girls.

Some of the major reasons for the significant decline in the demand for education relate to the affordability and quality of schooling for children. With the serious monetary, human and material resource constraints, "the factors affecting parents' demand for child schooling will include measures of the costs and benefits of schooling in both the current and future periods, as well as measures of the household's own budget constraints. Specifically, these include the:

- "Intrinsic value that parents place on an 'education';
- "Expected long-run benefits of schooling;
- "Current value of the child's time in productive activities inside and outside the home;
- "Other costs of schooling including school fees, the costs of other schooling inputs, and the availability of schools;
- "Quality of schooling available;
- "Household's current income and its ability to borrow for school expenses against future earnings."[268]

Economic pressures have led many young people (particularly males) and their families to reassess the value of education. Most pupils drop out of school because their parents cannot afford to pay school fees. With the rising living costs, children's labour is often needed at

home.[269] In the socio-economic environment prevailing in much of sub-Saharan Africa, there may be fewer children wanting an education—and fewer parents wanting their children to be educated. This is due in part to the reluctance of parents to make the considerable investment an education requires; in Tanzania, for example, families must come up with an estimated 26 million Tanzanian shillings* for eight years of primary school, four years of secondary education, and three years of university studies.[270] With the death of an educated young adult, the family loses the benefits of both future production and past education investment, leading to a kind of "secondary poverty".[271] The higher likelihood of educated offspring dying leads to a lower return on investment in education and therefore, perhaps, less willingness on the part of families to sacrifice for educational objectives. In sum, the uncertainties engendered by HIV/AIDS, "the weak family economic base, and the limited number of primary and secondary education graduates finding [their] way to further education and subsequently to formal employment" have driven parents to reconsider whether there is much to gain from keeping their children in school.[272]

When families with limited resources have to choose which children to send to school, boys are given priority over girls. Girls are often taken out of school during the third or fourth year of the primary cycle—before they are taught about HIV/AIDS. Many parents do not see the need to spend money on their girl children when they know the latter will eventually leave home. Another important consideration is the desire of parents to keep daughters away from what is perceived as the pernicious influence of a Western-style education—an influence seen to be increasing owing to the presence both of AIDS in the school and of sex education in the curriculum. In Uganda's Rakai District, some "parents reported that due to an increase in defilement and pregnancy among school girls, they were forced to withdraw their children from school completely since the schools had become a centre for spoiling young children."[272]

The growing disinterest in school may be partly attributable to "the increased randomness of the education provided. Especially in systems already affected by recession, debt, poverty, and natural or man-made disasters, the added absenteeism of both teachers and pupils due to the presence of HIV and AIDS ... will only make the education provided more sporadic and unsystematic."[193] As one study notes, students lose the sequence of subjects at school as their attendance (or that of their instructors) is affected.[273] Parents and children who recognize this deficiency and realize the implications of the many other factors mentioned in this section may see little point in continuing to spend their time and money in pursuit of such an education.[193]

The availability of teachers constitutes an important factor in assessing how families are affected by the impact of HIV/AIDS on the education sector. In 2000 UNAIDS and UNICEF developed an indicator that would provide a reasonable idea of the proportion of children in each country that had lost a teacher to AIDS. The results for 1999 were derived from a model based on the epidemiological models for estimating HIV prevalence and AIDS-related deaths, and on national data or estimates of primary school attendance and numbers of primary school teachers. Of the estimated 70 million children attending primary school in the 32 sub-Saharan African countries included in the present analysis, 1.2 per cent had lost a teacher to AIDS, with country rates ranging from less than 0.01 per cent in Madagascar to 4.0 per cent in Botswana (see figure XXI).

While the estimates of students who have lost a teacher to AIDS provide a measure of the impact on children, they do not convey a sense of the altered dynamics within the educational system per se; indicators reflecting teacher death rates and changes in the primary school

* Roughly equivalent to US$ 64,000 in 1993, around the time this information was issued, and approximately US$ 25,000 today.

population offer a clearer perspective in this regard. Projections indicate that between 2000 and 2010, an average of 2.1, 1.7, 1.4 and 0.5 per cent of the teachers in Zimbabwe, Zambia, Kenya and Uganda, respectively, will die of AIDS every year.[274] Similar rates have been forecast for Botswana, Malawi and Uganda.[275] A wider analysis included in the latter studies predicts that more than a quarter of a million teachers, or over 9 per cent of all those employed in sub-Saharan Africa, may die during the period 1999-2010. The projections are based on a model (the AIDS Impact Model, or AIM) applied to the education sector, and derive from several assumptions, among them that teacher mortality and morbidity rates parallel those in the overall adult population.[274] Contrary to the expectation that high AIDS-related mortality might increase the need for more college graduates to reduce dependence on unqualified teachers, AIDS may actually make it easier to lower student-teacher ratios, as the loss of teachers is more than offset by the decreased demand for education owing to the reduction in the primary-school-age population (see table 13).[274, 275] These formulations clearly illustrate the failure to apply either a family perspective or the concept of family capital. Although the decline in demand may ease some of the pressures in the education sector, this "relief" comes as a result of AIDS-related losses experienced by families at all income and education levels and the serious erosion of family capital (see box 9). While withdrawal from school represents a coping strategy for families affected by an AIDS-related illness or death, available data do not provide a breakdown of the precise reasons behind this decision; at present, there appears to be no information on the extent to which such withdrawal is based on the need to provide care to a family member, the need to restore the family's lost productive capacity, or the lack of financial resources to cover the costs of school fees, uniforms, and materials such as books and paper

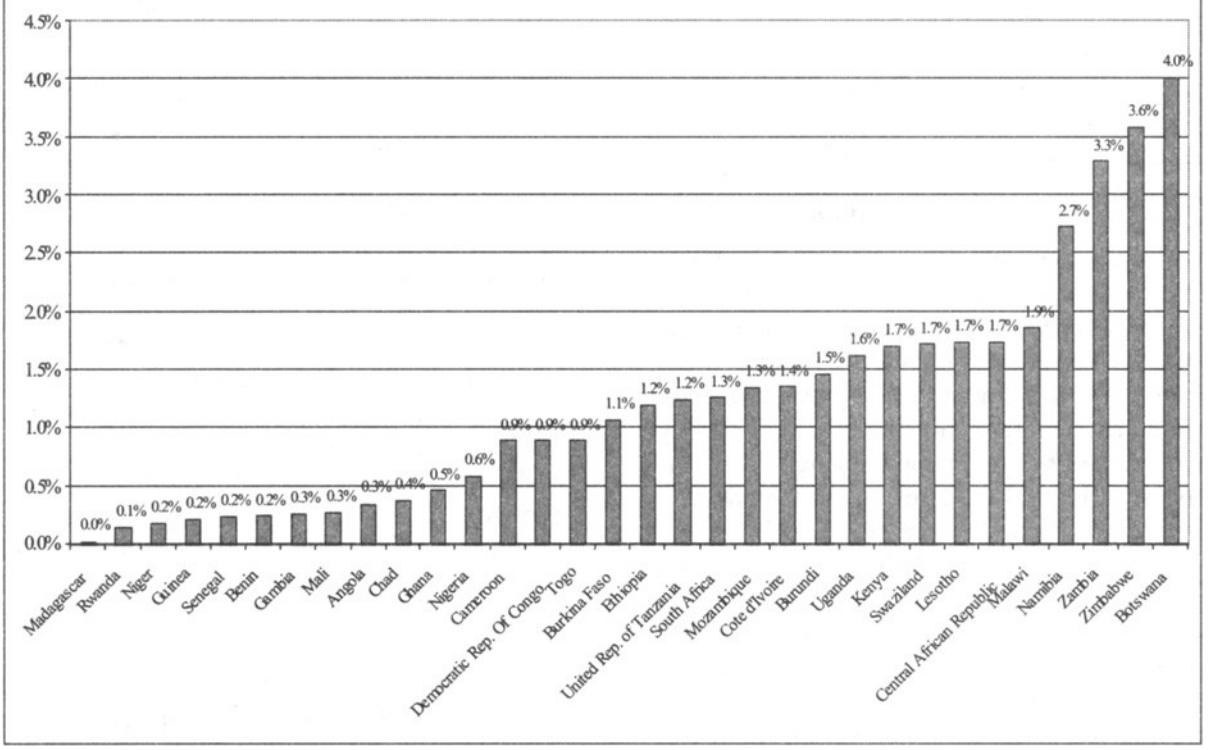
Student-teacher ratios may not be adversely affected by the withdrawal of children from school or by the reduction in the primary-school-age population; however, the costs of HIV/AIDS to the education sector, as reflected in the budgetary needs of the ministries of education, are not insignificant. In Zambia such ministry costs amounted to an estimated US$ 1.3 million to US$ 3.1 million in 1999, and are projected to total between US$ 10.6 million and US$ 41.3 million over the period 1999-2010.[276] These.

Table 13. The impact of HIV/AIDS on supply and demand in the education sector in four sub-Saharan African countries

	Zimbabwe	Zambia	Kenya	Uganda
Expected reduction in the primary-school-age population by 2010 (percentage)	24.1	20.4	13.8	12.2
Average annual percentage of teachers who are expected to die from AIDS, 2000-2010	2.1	1.7	1.4	0.5

Source: T.J. Goliber, for the AIDS Campaign Team for Africa (ACTafrica), "Exploring the implications of the HIV/AIDS epidemic for educational planning in selected African countries: the demographic question" (Washington, D.C., World Bank, March 2000).

Figure XXI. Percentages of children attending primary school who have lost a teacher to AIDS in 32 sub-Saharan African countries, 1999-2000



Source: Joint United Nations Programme on HIV/AIDS and United Nations Economic Commission for Africa, *AIDS in Africa: Country by Country* (Geneva, UNAIDS, September 2000) (UNAIDS/00.30E).

Box 9. The link between children's withdrawal from school and adult death within families

In studies from Côte d'Ivoire, children in families that had experienced an adult AIDS-related death had a significantly increased risk of being withdrawn from school in comparison with those in families in which no death had occurred (odds ratio = 1.34, 95 per cent confidence interval, 1.03-1.74). Both the income and the educational level of the head of household greatly affected the probability of a child being withdrawn from school in the two control groups (families in which an adult had died of causes other than HIV/AIDS and families in which no adult death had occurred); however, in families in which an AIDS-related adult death had occurred, neither of these variables affected whether a child was withdrawn from school.

Source: J. Pégatiénan and D.A. Blibolo, "HIV/AIDS, lagging policy response and the impact on children: the case of Côte d'Ivoire" (chapter 5), *AIDS, Public Policy and Child Well-Being* (Florence, UNICEF-Innocenti Child Development Centre, 2002); also available at http://hivaidsclearinghouse.unesco.org/.

costs include the salaries paid to absent teachers during illness, the expense of training additional teachers to replace those lost to AIDS, and the contractually required coverage of funeral costs. Although such costs represent only around 2.5 per cent of the budget, the burden AIDS places on the education sector may increase significantly as the epidemic continues and as resources decline, with alarming implications for the preservation of family capital.

9.6 Employment in the mining sectors

The mining industries in southern Africa emerged during the colonial era and flourished as a consequence of such legislation as the Glen Grey Act. Even aside from the effects of HIV/AIDS, cross-border labour migration for employment in the mines has effectively provided short-term income benefits at the expense of long-term development.[277] Economies and families providing such migrant labour are at the mercy of the mining industry. When policies change, as was the case when the Chamber of Mines of South Africa discontinued a century-old tradition of recruiting migrant workers from Malawi in 1988, the effects are felt in all the economic and social sectors of rural communities.[278] In the post-independence and post-apartheid period more attention has been given to education and training and to health and other social services such as the provision of pensions. However, some things have not changed.

In the mineral-rich areas, many of which are located in landlocked regions, large mining towns have evolved. A unique social characteristic of these towns is the concentration of male manual labourers and the absence of families. Recruited from various areas, the workers have very little, if any, education, with the exception of those needed for supervision and management. The mining sector has used people as expendable raw material. As the men work and live apart from their families, no aspect of their lives has permanence. With the men living in isolation, a burgeoning prostitution industry has evolved, leading to the spread of HIV/AIDS in these areas. There are many social and health problems in the mining towns, and there are often no alternatives to whatever services the mining companies may provide.[279]

Any conditions that adversely affect the efficiency of the labour force have an impact on both the mining industry and the families of the miners, and in recent years AIDS has seriously undermined the stability of both. Studies of HIV prevalence in the workforce in Botswana, South Africa and Zambia indicate that the highest rates are found among those in mining (18.0 per cent) and metal processing (17.3 per cent).[280] More than a decade ago it was anticipated that there would be lower individual productivity, absences from work owing to illness and illness-related social obligations, the need for additional health services, and more early retirement, as well as an increase in respiratory diseases, particularly tuberculosis.[218] This scenario appears to be playing out, the results of which include a lower return on investments in training and human resource development, as well as earlier and greater demands on pension and health insurance schemes, when these exist and are fairly implemented.[256] At the family level, there is an absence of men from economically active age groups in the villages from which the mineworkers are recruited. The populations of these emigrant villages consist mainly of old people and of small children, young girls and their mothers, many of whom have been abandoned by their husbands. The infected men return home to be cared for by the wives they deserted, and the family bears the burden. The cycle continues because there are enough poor men available for the mining jobs.

9.7 Summary: direct and indirect costs of HIV/AIDS

A study drawing upon data from 22 districts in rural Kenya[263] identified the characteristics of prime-age adults who died between 1997 and 2000 and estimated the impact of adult mortality on household composition, farm production, asset holdings, and off-farm income. The three major findings were as follows:

- Roughly half of the deceased prime-age men were in the highest per capita income quartile in the 1997 survey;
- Adult deaths were concentrated in particular areas. Of the 91 prime-age adults who passed away between the 1997 and 2000 surveys, a total of 36 (or about 40 per cent) were from the Nyanza Province, where HIV infection rates were known to be high. The results suggested that there might be a need for the Government and interested donors to intensify their safety net and education programmes in this province, while maintaining prevention programmes nationwide. Safety net programmes should specifically target households that have lost heads of household and spouses;
- After the death of a head of household or spouse, households were typically unable to remain the same size, as the numbers of both adults and surviving children decreased.

A study in Thailand identified and assessed the economic impact of HIV/AIDS-related illness on 116 rural households that had recently experienced an HIV/AIDS death. Direct costs included medical, travel and funeral expenses. Indirect costs included income forgone by the patient and other household members and income lost with the interruption of household production activities. The impact of socio-economic problems, social stigmatization, and discrimination against HIV/AIDS patients and their families was noted as well. There were several major areas of concern linked to the economic impact of HIV/AIDS-related illness and death in rural households. Many of these, highlighted elsewhere in this publication, include or relate to issues such as poverty, economic pressures, education, household labour, the care of orphans and older persons, social discrimination, the provision of health care, and traditional medicine.[281]

Table 14 provides a summary of the direct and indirect costs of HIV/AIDS at all stages, from the pre-infection to the post-mortem period.

Table 14. Direct and indirect costs of HIV/AIDS

Type of impact	Before infection	Period of latency	Period of illness	Period after death
Direct costs	Control and preventive measures	Testing, outpatient care and follow-up	Home and inpatient care, medications	Funeral and associated obligations
Indirect costs	Precautionary savings	Lower productivity of ill members	Lower productivity of ill members/loss of income for part of period	Income forgone from death
	Insurance	Reduction in consumption and investment (in anticipation of future costs)	Reduction in consumption and investment	Drop in family income and resources
	Acceptance of less risky but well-paid jobs	Opportunity cost of looking after ill members	Opportunity cost of looking after ill members	Poor health of some surviving members
	Intrafamily communication	Psychological cost to ill members and other family members	Psychological cost to ill members and other family members	Placement of orphans; support to child-parentalized or grandparentalized households
	Return of non-resident family members to family households	Cost to others infected and affected unwittingly by ill members	Return of other family members to family households for care and productive activity; loss of remittances	Return of other family members to family households for productive activity; loss of remittances

Source: Adapted from O. Solon and A.O. Barrozo, "Overseas contract workers and the economic consequences of HIV and AIDS in the Philippines", in *Economic Implications of AIDS in Asia*, D.E. Bloom and J.V. Lyons, eds. (New Delhi, United Nations Development Programme HIV/AIDS Regional Project, 1993), pp. 119, as cited and reproduced by D. Lim, "HIV/AIDS and Malaysian economic growth: national and regional dimensions", in *No Place for Borders: The HIV/AIDS Epidemic and Development in Asia and the Pacific*, G. Linge and D. Porter, eds. (New York, St. Martin's Press, 1997).

CHAPTER 10
CONCLUSIONS AND POLICY IMPLICATIONS

10.1 Summary and conclusions

In undertaking an examination and assessment of the family impact and family policy implications of HIV/AIDS, an effort has been made to move past the political and popular rhetoric to conduct a scientifically critical and socially responsible assessment of the rapidly increasing—and oftentimes changing—body of data, information and understanding of the three HIV/AIDS epidemics as they relate to the family. Too frequently, in the rhetoric surrounding the epidemics, there is little differentiation between that which may be considered a cause, that which may represent a consequence, and that which is likely to be incidentally associated with factors (perhaps as yet unidentified) that are more directly related to either the causes or consequences of the HIV/AIDS epidemics. For example, a lack of education among women and poverty are cited as factors underlying the spread of and vulnerability to HIV and are proposed as being at the core of sustainable action.[282] The current preliminary analysis of the situation among most of the sub-Saharan African countries suggests that poverty and a decline in education are more likely to be a consequence of, rather than a particularly important factor in, the perpetuation of the epidemic. Furthermore, there is too quick a tendency to apply the "proof" of causality or consequence in one setting to other settings. Child marriage may be associated with prostitution in some contexts but not in others, and the same is true with regard to the link between male circumcision and low HIV prevalence.

Because resource limitations made it necessary to rely on available published (rather than primary) data sources, several mathematical models were developed and utilized to estimate the total numbers of families, as well as the numbers and proportions of families affected by HIV/AIDS, in the more than 30 sub-Saharan African countries for which reasonably reliable and relevant data were available for the period 2001-2003. While the estimates derived may not be exact, they are believed to reflect a reasonably accurate approximation of the prevalence of families affected by HIV/AIDS in the countries studied. In the course of this analysis, a number of factors have been identified that appear to be statistically associated with the variations in adult HIV prevalence and the incidence rates of families affected by HIV/AIDS. Two such factors include the prevalence of household arrangements in which children have two living parents but reside with the mother alone or with a foster family (most often one within the child's family network). Both of these living arrangements are strongly associated with lower poverty levels, as measured by the HPI or poverty indicators at the household or national level. It should be noted that country-based analysis is characterized by certain limitations. For example, household-based HIV surveys from three countries using a common protocol show wide variations and different patterns in the statistical association of HIV prevalence with such variables as wealth, the prevalence of male circumcision, numbers of sexual partners in the previous 12 months, women in polygynous unions, and the age of women at first sexual encounter.

Family capital constituted the framework within which the impact of HIV/AIDS on the family was examined. A number of possible indicators of family capital were available from DHS and MICS reports, including the living arrangements of children, orphanhood, the primary education of women and children, traditional practices and, as specifically related to HIV/AIDS, spousal communication and family caregiving. It was not possible to analyse the association of these characteristics with family households; however, tests were conducted to identify the variations in the correlation of these characteristics with adult

HIV prevalence and the incidence rates of families affected by HIV/AIDS among the countries studied as part of an exercise designed to generate reasonable hypotheses. While the strong association of many of these characteristics with the HIV/AIDS indicators does not imply causality, the fact that a significant linkage has been established is sufficient to warrant the collection and analysis of aggregated family-household data on HIV/AIDS and the family. Data on the HIV status of absentee family members would be useful; however, a fairly sophisticated and logistically difficult methodology would be required to maintain participant anonymity and confidentiality in community- and household-based research. Further assessment and development of the concept and indicators of family capital would also seem warranted.

The impact of HIV/AIDS on the family varies in both form and magnitude and is unevenly distributed among communities. It is the unique social, economic and cultural circumstances of different families and communities within this context that will govern the nature, scope and likely effectiveness of relevant family policy options. Many families affected by HIV and all families affected by AIDS (through the stages of illness and death) suffer losses of income and family resources as economically active members become less productive and as expenses are incurred for treatment, travel for medical care, and funerals. The decline in income and capital is particularly rapid among those families dependent on the remittances of non-resident members who return home for care with the onset of AIDS.

Research and policy considerations relating to HIV/AIDS and the family have been dominated by two perspectives: the role and resource potential of the family both in efforts to control HIV/AIDS and in caring for those living with HIV/AIDS; and the orphan crisis. The focus on these two areas, as important as they are, has deflected attention from the critical threat HIV/AIDS poses to the integrity and functioning of the family.

Largely influenced by the medical model of HIV/AIDS, the research agenda, programme considerations and policy options for HIV/AIDS and the family have been informed by, and developed on the basis of, the following:

- The family as a resource for the individual coping with medical illness;
- Family dysfunction or pathology as a factor contributing to disease;
- Family characteristics as they influence the relationship with the health system;
- Family factors as determinants of the clinical course of specific illnesses.[283]

Again, as useful as this model may be for developing strategies to deal with the epidemics and facilitate the prevention of HIV/AIDS and the care and treatment of infected individuals, it does not address those needs deriving from the impact of the epidemics on the family as an economic, social, and cultural entity per se. The focus must shift to maintaining the integrity of the family and family capital in order to ensure the effective functioning of the family so that the wide-ranging needs of all family members can be met in an ever-changing environment.

It is only in the past few years that a significant body of information on AIDS and the family has emerged from research and situation analysis in developing countries, though it is largely limited to studies of sub-Saharan Africa and Thailand and isolated reports from other countries or regions. Little or no published research relevant to the family and HIV/AIDS has come out of areas such as South-East and East Asia, Latin America and the Caribbean, East and Central Europe, or the former Soviet Union. The lack of research in these regions blocks any attempt to draw global conclusions or formulate generalized recommendations from the existing research relating to the sub-Saharan African experience.

From the information available, it is possible to draw some general conclusions regarding the impact of HIV/AIDS on most families in a range of settings (but particularly in sub-Saharan

Africa), and to characterize the families affected by HIV/AIDS:

- Many families live in circumstances that make them vulnerable to HIV transmission;
- The family member initially infected is often an economically active resident or non-resident adult male; other members of the family may be vulnerable as well and either voluntarily or involuntarily exposed to HIV-risk behaviours;
- Both cohabitation and shared lifestyles often result in multiple family members being infected;
- The overwhelming majority of families with an HIV-infected member are unaware that they are (or are about to become) a family affected by HIV/AIDS.

Once a person infected with HIV is aware that he or she is seropositive, either of the following may occur:

- Other family members are not informed, or only selected members are informed, though usually not right away;
- Other family members become aware of the situation when the symptoms of AIDS or an AIDS-related illness are more clearly manifested and the infected individual is unable to work or function normally.

The family affected by HIV/AIDS is often:

- Obliged to divert its time and resources away from such priorities as economic production and education to the provision of personal and health care for the member with HIV/AIDS;
- Subject to stigmatization and discrimination, which frequently leads to isolation from the community and extended family; in certain cases this may play a role in the immediate family's rejection of the infected member;
- Poorly prepared for the future owing to the failure to plan for the continued well-being of dependent family members (including children and older persons) and the care of infected and affected family members (including uninfected dependants) during the period of illness and in anticipation of death;
- Unable to stay together as a nuclear unit. Depending on the economic and caring role of the deceased, resources and caring functions may be sufficiently reduced to threaten the viability of the family, which may then dissolve.

It is not known whether there is a point at which the proportion of families affected by HIV/AIDS and their capacity to function and cope reach a critical level such that a dysfunctional or deteriorating community is produced as a consequence of the loss of family capital and the deterioration of the physical and social environment and productive capital (land, tools and skills).

Table 15 presents a partial summary of the potential effects of HIV/AIDS on the family, on children, and on the community.

The following varies from one setting to another:

- How, when and under what circumstances the family is vulnerable and becomes affected by HIV/AIDS;
- The prevalence and incidence rates of families affected by HIV/AIDS;
- The nature and extent of social and family capital available to families;
- Whether social and family policies and programmes exist and are applied to promote, protect and support the accumulation and use of social and family capital in order to preserve the integrity and functioning of the family.

It is asserted here that the promotion, protection and support of the family and the various dimensions of family capital—rather than the non-specific call for poverty reduction—lie "at the core of a sustainable solution to HIV/AIDS".[282] A more family-focused approach would require in-depth analysis within countries and among major groups with respect to the structure and

Table 15. The potential impact of HIV/AIDS on families

Potential impact of AIDS on family capital	Impact of AIDS on children	Community stresses
Relationships ▪ Intrafamily conflict; ▪ Rejection of family member; ▪ Stigmatization, discrimination and isolation; ▪ Death of member, grief; ▪ Increased number of multi-generational households lacking middle generation; ▪ Change in family composition and in adult and child roles. *Resources* ▪ Impoverishment; ▪ Loss of labour; ▪ Loss of income for medical care and education; ▪ Forced migration; ▪ Time and money spent for funerals. *Resilience* ▪ Demoralization; ▪ Stress; ▪ Inability to parent and care for children; ▪ Dissolution; ▪ Long-term pathologies (increased depressive behaviour in children).	▪ Loss of family and identity; ▪ Depression; ▪ Reduced well-being; ▪ Increased malnutrition, starvation; ▪ Failure to immunize or provide health care; ▪ Decline in health status; ▪ Increased demands on labour; ▪ Loss of schooling/ educational opportunities; ▪ Loss of inheritance; ▪ Forced migration; ▪ Homelessness, vagrancy, crime; ▪ Increased street living; ▪ Exposure to HIV infection.	▪ Reduced labour; ▪ Increased poverty; ▪ Inability to maintain infrastructure; ▪ Loss of skilled labour, including health workers, teachers and agricultural extension workers; ▪ Loss of agricultural inputs and labour; ▪ Reduced access to health care; ▪ Elevated morbidity and mortality; ▪ Psychological stress and breakdown; ▪ Inability to marshall resources for community-wide funding schemes or insurance.

Source: Adapted from S. Hunter and J. Williamson, "Developing strategies and policies in support of HIV/AIDS-infected and affected children", Health Technical Services Project, TvT Associates, the Pragma Corporation (Arlington, Virginia, USAID, HIV/AIDS Division, 1997).

functions of the family, identification of the elements of family capital critical to those functions and the needs of families in the various social, economic and cultural contexts of different countries and communities around the world, and the adaptation of relevant solutions to the specific conditions prevailing in these settings.

10.2 The future of the family

In both the report prepared by the Secretary-General for UNGASS (A/55/779) and the Declaration of Commitment issued at that Special Session, it is recognized that the family bears the brunt of the HIV/AIDS epidemic. Traditional support systems, previously effective even in resource-poor environments, are beginning to weaken under the strain of contracting resources and the foster-care burdens shouldered by grandparents and other extended relatives heading reconstituted households. While orphanages are not common in the African setting, they are becoming an increasingly attractive option for foster families under stress.

HIV/AIDS not only threatens the functioning capacity of the community, but in many settings appears to seriously compromise the essential viability of the family. In a number of areas, efforts to maintain or enhance family capital—including temporary or long-term economic migration in order to increase income, or the practice of traditions (such as levirate) intended to strengthen family bonds and support—may be aggravating the epidemics. This is suggested by the time trends for HIV/AIDS indicators, the changes in vetting practices for prospective marital partners, the high rate of HIV among widows, the emergence of new patterns in family structure and function, and the dramatic loss of family capital in some settings.

Some persistent and disturbing patterns have emerged in connection with the incidence and prevalence of families affected by HIV/AIDS. The wide differences in HIV prevalence in urban settings in some sub-Saharan African countries have attracted the attention of researchers and public health authorities; however, the variation of as much as 30-fold in the annual rates at which families are newly affected by HIV/AIDS has thus far gone unrecognized (see table 1 and figure XXII). The relatively slow increase in the rates at which families are newly affected by HIV/AIDS in some countries can be deceiving, as it obscures the enormity and urgency of the overall situation; in the three countries with annual incidence rates exceeding 1.5 per cent a total of 154,000 families are newly affected each year, while an additional 75,000 families are affected in the 11 countries in which the corresponding incidence rates are lower than 0.15 per cent (see table 1). Particularly disturbing is the apparent net annual decline in HIV/AIDS-free families in Lesotho, Namibia, South Africa and Zimbabwe (see figure XXII). At least one of these countries, Lesotho, appears to have passed the "tipping point", at which the prevalence of affected families is sufficiently high that entire communities are rendered dysfunctional as a direct consequence of the epidemics;[187] AIDS may well be the first and only medical condition in modern times to produce a "failed State". As previously noted, poverty appears to contribute little to explaining these patterns.

The exceedingly high rates at which families are newly affected by HIV/AIDS in the countries hardest hit in southern Africa correspond to the relatively late onset of the epidemic in these countries. In South Africa, the first two cases of AIDS were confirmed in 1980,[284] and by 1990 there were only 554 reported cases; a mere third of these were attributed to heterosexual transmission.[285] The comparable figure for Lesotho was a cumulative total of 23 by 1990.[286] In 1985, 11 per cent of the women tested in antenatal clinics in Uganda were HIV-positive, while the corresponding rate in South Africa was less than 1 per cent;[284, 287] by 2002, however, the rates in urban and rural Uganda were 6 and 4.7 per cent respectively, while the combined rate for South Africa was 28 per cent.

The longstanding labour and land policies that were instituted and have been maintained to

ensure a large workforce for mining and manufacturing and that have separated large numbers of adult males from their rural-based families appear to have been a factor in the inter-country and urban-rural spread of the HIV epidemic. Traditional practices believed to have increased the scope and magnitude of the epidemic and the rate at which it has spread include levirate, the absence of male circumcision, and delayed marriage among men wishing to amass sufficient wealth to pay a "bride price".

The greater biological and social vulnerability of women, particularly adolescents, accounts for the wide sex differences in HIV-positive rates among the young. Sexual harassment, exploitation and violence, as well as the exchange of sexual favours for material or social gain, contribute to the higher rates of seropositivity among young women in many settings. In areas in which pregnant women have been monitored for more than a decade, there has been a marked increase in HIV infection rates among women.

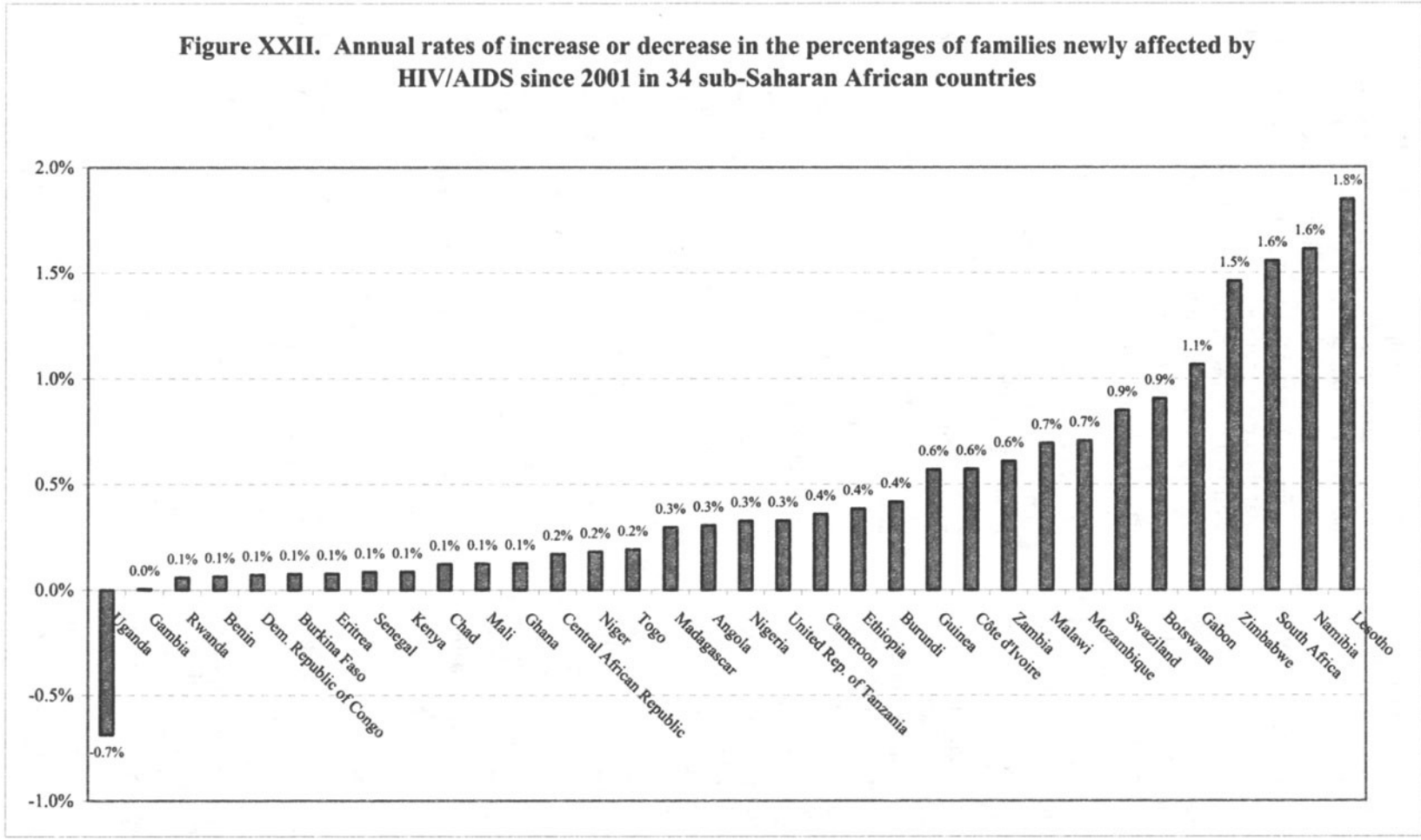
Through its impact on farming families the HIV/AIDS epidemic undermines rural health, weakens agricultural and educational infrastructures, jeopardizes food security, and threatens the integrity of communities. The proportion of families affected is greater than the proportion of HIV-positive adults; in some areas of Africa half of all families are directly or indirectly affected by HIV/AIDS.

While family networks are extensive in many sub-Saharan African countries, the burden of care is increasingly falling on older persons[288]—most often the parents of multiple adult children who have died of AIDS and left behind large numbers of dependent grandchildren. Ultimately, parentalized children must assume responsibility for these grandparent-headed households or confront the very real probability of eventual household dissolution. In some areas the overwhelming numbers of orphans have disrupted traditional patterns of patrilineal orphan care, resulting in increased reliance on "culturally inappropriate" living arrangements for children who have lost one or both parents.[289]

As the far-reaching implications of HIV/AIDS are becoming better understood, many individuals and families are taking steps to protect themselves from both the disease and social ostracism. Two contradictory trends appear to be emerging as VCT becomes more widely available: an avoidance of voluntary counselling and testing owing to the fear of stigmatization or, if tested, the fear of disclosure; and an increasing demand for VCT among prospective marital partners or their families. This cautionary attitude is reflected elsewhere; the practice of levirate, once a means of guaranteeing the security of a widow and her children, is now being abandoned based on the presumption that a husband's death is AIDS-related. The stigmatization a woman suffers—whether she is affected or infected, widowed or unwed—because she is part of a family affected by HIV/AIDS may drive her out of the community and away from her family, and with no other means of support she may turn to commercial sex work to survive.

For many communities, and even some countries, the three elements of family capital—relationships, resources and resilience—are under tremendous strain, or have been seriously diminished or virtually lost. In the absence of specific policies and programmes that protect and preserve the integrity of the family and family capital, not only will families collapse and dissolve, but entire communities may be affected to the extent that human security and the integrity of such communities are threatened.

Figure XXII. Annual rates of increase or decrease in the percentages of families newly affected by HIV/AIDS since 2001 in 34 sub-Saharan African countries



Sources: Data for the models and analysis were obtained from the 34 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2002 Revision* (CD-ROM) (New York, 2003) (United Nations publication Sales No. E.03.XIII.8).

Much attention and thought has been focused on the needs and family circumstances of children orphaned by AIDS, but beyond the rhetoric, little attention has been given to strengthening the capacity of families to deal with the multiple challenges created by the HIV/AIDS epidemics before they are affected by either HIV or AIDS. In broad terms, this would involve efforts to ensure that families acquire and/or retain the capacity to satisfy the basic needs of their members. Achieving this fundamental objective has become increasingly difficult, as both the process of development and the HIV/AIDS epidemics have changed the nature and structure of the family, possibly at a rate exceeding the adaptive capacity of many families. The challenges facing the family in such a context extend beyond the medical model of prevention and care. Family capacity-building should involve promoting intrafamily communication; protecting and promoting the dignity, rights and responsibilities of its members; and enhancing the family's capacity to plan for the protection and further accumulation of family capital. With the erosion of family capital, the ability of each family to perform its normative role declines, imposing an added burden on community and extra-familial institutions. In a worst-case scenario, the family may dissolve and disperse, which often leaves the surviving members unprepared to function optimally and productively in the community or society. Once a critical mass of families is thus affected, a community may no longer be capable of meeting the needs of either affected or unaffected families.

10.3 Policy implications

Family-focused policies must be among the priority responses to the HIV/AIDS epidemics. Family-specific data and indicators are needed to monitor the impact of such policies. All three epidemics have demonstrated the potential to seriously impair the capacity of families to fulfil their needs, roles and responsibilities in an environment transformed by AIDS. Within the framework of appropriate policies and programmes, family capacity-building can serve as an additional, critical locus in efforts to limit the adverse impact of HIV/AIDS. Two complementary sets of policies should be developed to address the challenges of HIV/AIDS from a family perspective; specifically, attention should be given to policies that directly affect the integrity, functioning and well-being of the family; and to those that focus directly on the epidemics but are likely to have a profound impact on family functions and family capital.

The objectives of promoting, protecting and supporting the accumulation and maintenance of family capital should provide the framework for social and family policies and programmes undertaken to address the epidemics. Taking into account the wide cultural, social and economic variations within and between countries, policies aimed at fostering intrafamily communication, gender equity and the elimination of harmful traditional practices are essential for the health and well-being of the family and its members, as they provide a means of strengthening or preventing the loss of family capital (measured in terms of assets and liabilities); of direct relevance to the present analysis is the fact that these are among the most effective measures families can take to prevent HIV/AIDS. The progression from HIV to AIDS and from AIDS to death is often rapid and unrecognized, and in both cases family capital is quickly eroded. It is therefore essential to ensure increased access to and utilization of VCT and to scale up antiretroviral treatment programmes so that families are given an opportunity to strengthen, protect and accumulate family capital, placing them in a better position to plan for and meet their future needs. It is strongly suggested that "family resilience" be added to the UNAIDS call for "forward-looking measures that restore social resilience" in responding to the impact of AIDS in such areas as food security, orphans, and human-resource capacity in institutions and bodies in the public and private sectors.[6]

The social and cultural environment creates and legitimizes the prevailing gender relationships and the attitudes and norms

governing the expression of human sexuality; however, it is within the family that norms and standards—many of which have contributed to the explosive spread of HIV and AIDS—are translated into relationships between men and women and the socialization of children. There have been few policy or programme efforts directed at a family locus for change—a reflection of the fundamental unwillingness of countries to deal with the issue and implications of human sexuality, which lies at the core of the HIV/AIDS epidemic. For decades, family planning programmes have focused on the technical aspects of contraception, completely ignoring the emerging scientific knowledge of human sexuality. The adaptation and application of this knowledge in different social and cultural contexts is critical for promoting reproductive health and responsible sexuality. Unfortunately, the lack of awareness of the knowledge and skills individuals require in negotiating equitable and sexually responsible human relationships has rarely been addressed. Health workers and educators should, at a minimum, be equipped with the knowledge and communication skills needed to adapt and convey the required scientific information in an age-appropriate and culturally sensitive manner within their communities. It is in direct response to the global HIV/AIDS pandemic that these issues are starting to be placed on the policy and programme agendas of Governments and of national and international institutions and organizations—often in the face of great resistance. It will take even greater determination and sensitivity to culturally adapt this knowledge and make it accessible to families.

Stigma and discrimination present another conundrum in efforts to better define the impact, strategies and policies relevant to AIDS and the family in the multiplicity of economic, social and cultural circumstances found in most countries. In obtaining a more precise assessment of the HIV/AIDS epidemics, and because of the ethnic clustering of various traditional practices, gender relationships and sexual behaviours, there is a risk of the HIV/AIDS stigma being attached to pre-existing stigmas (such as those linked to negative racial and ethnic stereotypes) and to discrimination against women and sexual minorities.[6]

The overall objective of family policy is to promote, protect and support the integrity and functioning of the family by ensuring that family capital can be accumulated and strengthened. Achieving this goal requires the adoption of policies that reinforce healthy family relationships, protect and increase family resources, and strengthen the resilience of families in an ever-changing environment. Historically, most societies, including such institutions as the family, have demonstrated the ability to adapt to change over time. However, the HIV/AIDS epidemic has swept through many countries in less than a generation, overriding social and cultural adaptive mechanisms. Unfortunately, many political and religious leaders at both the local and national levels have been slow to recognize the scope and nature of the epidemics, tending towards disbelief or denial, or substituting ideology for scientifically established solutions. Political and religious leaders and others in positions of authority are morally and—insofar as their countries have subscribed to and ratified any or all of the key international human rights instruments—legally obligated to take socially responsible action on the basis of scientifically sound information to address the issues of AIDS and the family. The legislative and programme frameworks for effecting such policies are the legally binding international treaties and conventions ratified by an overwhelming majority of countries,[16] including the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child.

There is no single format or perspective for the development of family-relevant policies in response to HIV/AIDS. Many of the priority policies aimed at controlling the epidemics have positive implications for families and may therefore be considered supportive of family policies. However, additional policies and

programmes that go beyond or overlap with those in other sectors are required to address the needs of families more directly.

An enabling legal framework is essential for supporting community- and family-based policies and programmes aimed at mitigating the challenges faced by HIV/AIDS-affected families. Legislation, regulations and, where relevant, customary law should be introduced, strengthened or modified to ensure that affected families have access to those entitlements contributing to family capital, including inheritance distributions; life, employment and health insurance; health care; food security; and education. Economic barriers to the latter three components should be removed or greatly reduced.

Family policy may be examined in terms of the impact of HIV/AIDS on the family at different stages and the specific needs arising therefrom. The respective stages and optimal policy responses include the following:

▶ *Before any family member is infected with HIV.* This is the period during which preventive policies are needed. Examples include policies aimed at eliminating child marriage, human trafficking, the commercial sexual exploitation of children, traditional practices harmful to the health and well-being of women and children, and discrimination against women and girls in such areas as education, health care, property ownership and inheritance. Policy-supported programmes might include the development of culturally relevant, age-appropriate curricula and materials for training and orientation in human sexuality and gender issues for health workers, teachers, and political, community and religious leaders. The active involvement of all stakeholders should be a guiding principle in the development of such materials. Authority structures within families constitute one of the major barriers to achieving effective intrafamily communication and decision-making. Development strategies that promote microcredit and income-generating activities for women are among those likely to improve intrafamily equity. It has not yet been established whether such strategies might contribute to more responsible sexual behaviour. The development and promotion of VCT should include a family and family capital protection, promotion and support component that incorporates, inter alia, anti-discrimination legislation.

▶ *When circumstances are such that a family is vulnerable to HIV, and family members are likely to engage in HIV risk behaviours or may be subject to exploitation or abuse, increasing the risk of HIV exposure.* Policies addressing the challenges associated with this stage should be designed to optimize risk reduction and promote VCT among risk groups. Translating such policies into programmes requires the establishment of a participatory framework in which families, community members and relevant social, religious and political institutions and leaders work cooperatively towards a common goal. As a policy principle, such programmes should incorporate community-based approaches, including family-to-family and peer counselling and support;

▶ *When the first asymptomatic HIV-positive family member has informed one or more other family members of his or her HIV status.* At this stage, with the family characterized as being a family affected by HIV/AIDS, family policies should be directed towards prolonging the productive life of the person living with HIV, minimizing intrafamily transmission (including MTCT), and promoting the accumulation and strengthening of social and family capital. Ensuring food security and adequate nutrition and health care will allow many of those with HIV/AIDS to maintain their productive capacity for an extended period. Financial and discriminatory barriers to education, health care and continued employment should be eliminated. As resources are mobilized, the availability of subsidized, affordable antiretroviral treatment becomes an increasingly important component for the protection and support of the family;

▶ *When the HIV-positive family member, whose serostatus may or may not have been known, becomes symptomatic with AIDS, an AIDS-related illness, or another illness and is less able to engage in productive labour activities and fulfil expected family roles and functions.* This is a stage of severe stress, during which all the elements of family capital may be strained, constricted and eroded. Internally and externally, the family or some of its members may suffer from the effects of discrimination and stigmatization. If planning for the future has not yet begun, this is the stage at which such planning becomes critical for the survival of individual family members as well as the family as an entity. The range of policies relevant at this stage should include a focus on community-based support for families affected by HIV/AIDS, subsidies to cover school fees and ensure food security, efforts to maintain the productive capacity of those living with HIV/AIDS (as noted above), and respite arrangements for family caregivers. Community-based organizations comprising families affected by HIV/AIDS have been very effective in some countries;

▶ *When a family experiences an AIDS death, particularly when it is a parent who dies and dependent children are orphaned.* At this stage the burden of maintaining the essential functioning of the family, and devoting particular attention to the health, nutritional and developmental needs of surviving dependent children, typically falls on those unprepared, and often least able, to provide such support. To the extent possible, the integrity of the family should be maintained. For families affected by HIV/AIDS, facilitating the formation of a partnership between the State, the community and the family network should be among the priority strategies for conserving and protecting family capital. Insofar as the family network can absorb a certain measure of responsibility and address the needs of surviving members within the family framework, additional community support, respite and mentoring should be provided. The needs of a family affected by an AIDS death should be met without discrimination or violation of the rights of that family. The development of an ombudsman system should be considered as a means to protect the rights of the surviving members of the family, and policies on inheritance and guardianship should be consistent with international human rights norms and translated into appropriate regulations or legislation.

Family policy requirements may also be examined within specific environmental and economic contexts. A number of rural/agricultural communities in different parts of Africa were studied using a common framework developed by FAO. On the basis of the research findings, the coping responses of rural families affected by HIV/AIDS were categorized as follows:[290]

- Strategies aimed at improving food security;
- Strategies aimed at raising and supplementing income so that household expenditure patterns may be maintained;
- Strategies aimed at minimizing the loss of labour.

One of the conclusions of the FAO studies is that the coping strategies most frequently employed are those not requiring any cash; such strategies include reallocating labour within the household, taking children out of school, diversifying household crop production, and decreasing the area under cultivation. "While some of the coping responses can be reversed, some, such as [the] withdrawal of children from school, are often irreversible. These could be viewed as short-term strategies with long-term consequences for survival."[290]

Within this framework, policy options that can be adopted to protect family capital and strengthen the coping capacity of families affected by HIV/AIDS include:

- Improving the access of affected families to limited resources such as labour, land, capital, draught power, and management skills;

- Promoting the optimal use of available resources through the introduction of improved technologies;
- Facilitating the creation of income-generating activities to improve the economic situation of affected families;
- Empowering affected groups such as child-headed households, widows, grandparents, youth, orphans, and sex workers by establishing systems of self-support, the aim being to reduce further vulnerability and strengthen resilience.[290]

Another policy perspective with implications for the family and family capital relates to the development of the family's human resources through education. Despite their lack of resources, some countries with high rates of HIV/AIDS, such as Malawi and Uganda, have adopted a free-education policy that offers orphans a vital source of support. Malawi has also drawn up a national policy for orphans and is moving towards a community-care approach; South Africa is currently trying out similar policies.

In a number of countries the situation in the education sector has reached crisis proportions, and immediate action is required. High rates of morbidity and mortality from HIV/AIDS are rapidly depleting the ranks of active teaching and administrative staff in many areas, leading to reductions in teaching hours and increases in class size. Even in situations in which AIDS-related pupil dropout rates have been sufficient to offset teacher losses and student-teacher ratios appear more reasonable, educational continuity is seriously lacking. These trends reduce educational opportunities and lower the quality of education for all children, whether their families are affected or unaffected by HIV/AIDS. To minimize the net losses of personnel in the education sector, teacher training and recruitment must be accelerated. Systems need to be developed to ensure that the increasing numbers of orphans remain in school, and solutions must be found for their long-term care and development.

In communities in which large numbers of families have been affected by AIDS deaths and orphan prevalence is high, the strengthening of social and family capital—in part through the provision of subsidies to community-based organizations and affected families—may be critical to the healthy development and education of children who have lost one or both parents to AIDS, and ultimately to the survival of the family.

Support should be provided for community coping mechanisms to strengthen the capacity of families to care for orphans. Outside organizations can develop partnerships with community groups, helping them respond to the impact of AIDS by building upon existing concern for orphan families. They can help affected communities develop orphan support activities that encourage caring responses by community leaders and relatives and that discourage property-grabbing and orphan neglect. Material support channelled through community groups and provided to destitute families at critical times can strengthen family coping mechanisms. Income-generating activities should build upon communities' existing capabilities and benefit the most vulnerable orphan households. In sum, the establishment of support activities and organizations for infected individuals and their families can contribute to family capital accumulation in a multitude of areas so that all concerned are better equipped to deal with the effects of the disease.[188]

The following five support strategies are highlighted in a recent review:[131]

- Strengthen and help preserve the capacity of families to protect and care for their children;
- Mobilize and strengthen community-based responses;
- Strengthen the capacity of children and young people to meet their own needs;

- Ensure that Governments develop appropriate policies (including legal and programme frameworks) and essential services for the most vulnerable children;
- Raise awareness within societies to create an enabling environment for the support of children affected by HIV/AIDS.

The family's objectives with respect to the HIV/AIDS epidemic are relatively straightforward and include the following:

- Preventing HIV acquisition among family members;
- Preventing HIV/AIDS transmission within the family;
- If HIV seropositive, delaying the progression of the infection to AIDS or AIDS-related illness and death.

While these objectives are easily stated, experience has shown them to be difficult to achieve, particularly in the absence of social, political and material support. The types of support required include policy options and programmes that can:

- Identify and strengthen the capacity of vulnerable families to resist becoming affected by HIV, with action taken to change family practices that perpetuate the epidemic and contribute to further suffering;
- Ensure that families with a member already infected by HIV have the knowledge, skills and means with which to limit further transmission within and outside the family;
- Identify and strengthen the capacity of families affected by HIV to delay the onset of AIDS, and to plan and prepare for the eventual progression of the disease and death;
- Prevent stigmatization and discrimination within the family and community and by social institutions;
- Identify families affected by AIDS; support them in the performance of their family functions; and protect the rights and well-being of the surviving members of families affected by an AIDS death, providing family-like environments and other alternatives for children orphaned by AIDS and "deconstructed" families.

Much remains to be done in defining the relationship between AIDS and the family and assessing its implications for human and policy development. The following are needed in particular: projections of the magnitude of the problem of affected families; agreed definitions and methodologies for estimating the incidence and prevalence of families affected by HIV/AIDS and identifying relevant trends; the development and testing of a survey module to identify, quantify and qualify family networks; the identification of priority needs in the mobilization of social capital; and country case studies and policy analyses. There is an urgent need for a common framework, locally adaptable to allow the application of rapid research *cum* rapid evaluation methods for country- and culture-specific policy and programme development in support of families facing the personal, social, cultural and economic challenges deriving from AIDS in their societies.

Heretofore, not only have national and international authorities failed to systematically examine the family impact and policy implications of the HIV/AIDS epidemics, but in concentrating on macroeconomic models they have also failed to undertake family impact perspective in the course of advocating and developing the social and economic development policies and programmes meant to address poverty. Too often they have resorted to the refuge of rhetoric in attributing the epidemics of HIV/AIDS to poverty and the lack of development in countries and communities. As we have noted, HIV/AIDS is not a disease of poverty. It is an impoverishing disease. The historical legacy and continuation of economic development and labour policies that separated fathers from their families seems to be an important feature of the appallingly rapid

increase in families newly affected by HIV/AIDS in several countries and many communities. A few are dangerously close to the "tipping point" characterized by Levi-Strauss and cited at the opening of this publication, "There would be no society without families, but equally there would be no families if society did not already exist."[291]

Even as much remains to be done, much more can be done with what we know and what is knowable with available data. Unprecedented progress has been made in research from the laboratory to affected communities. Unfortunately knowledge is not enough. Family-relevant indicators are insufficiently developed, rarely applied and yet to be monitored. Appropriate action in too many areas is impeded by misinformation, myth, inertia and denial, which can only be overcome by political will matched by the international, national and local mobilization of technical and material resources. While preventing and delaying each phase of the progression from HIV infection to AIDS-related death would have a beneficial affect on the family, the further development of and a focus on promoting, protecting and supporting family capital would contribute both to sustainable development, and efforts to control the three epidemics of HIV/AIDS.

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Annex I
WHO Staging System for Patients Infected with HIV*

Stage 1:

- Asymptomatic
- Persistent generalized lymphadenopathy

Stage 2:

- Weight loss: 5-10 per cent of body weight
- Minor mucocutaneous manifestations (seborrhoeic dermatitis, prurigo, fungal nail infections, recurrent oral ulcerations, angular stomatitis)
- Herpes zoster within past five years
- Recurrent upper respiratory tract infections (for example, bacterial sinusitis)

and/or

- Performance scale 2: symptomatic, normal activity

Stage 3:

- Weight loss: >10 per cent of body weight
- Unexplained chronic diarrhoea for longer than one month
- Unexplained prolonged fever (intermittent or constant) for longer than one month
- Oral candidiasis
- Oral hairy leukoplakia
- Pulmonary tuberculosis within the past year
- Severe bacterial infections (for example, pneumonia, pyomyositis)

and/or

- Performance scale 3: bedridden for less than 50 per cent of the day during the last month

Clinical stage 4 (AIDS):

- HIV wasting syndrome†
- *Pneumocystis carinii* pneumonia
- Toxoplasmosis of the brain
- Cryptosporidiosis with diarrhoea for more than one month
- *Cryptococcus*, extrapulmonary
- Cytomegalovirus infection of an organ other than the liver, spleen, or lymph nodes
- Herpes simplex virus infection—mucocutaneous for more than one month or visceral of any duration

- Progressive multifocal leukoenc leukoencephalopathy
- Any disseminated endemic mycosis
- Candidiasis of the oesophagus, trachea, bronchi or lungs

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* World Health Organization, "Acquired immune deficiency syndrome (AIDS): interim proposal for WHO staging system for HIV infection and disease", *Weekly Epidemiological Record*, vol. 65 (1990), pp. 221-228.

† Defined by the Centers for Disease Control and Prevention (CDC) as weight loss of greater than 10 per cent of body weight, plus either unexplained chronic diarrhoea (greater than one month) or chronic weakness and unexplained prolonged fever (greater than one month).

- Atypical mycobacteriosis, disseminated
- Non-typhoidal salmonella septicaemia
- Extrapulmonary tuberculosis
- Lymphoma
- Kaposi's sarcoma
- HIV encephalopathy*

and/or

- Performance scale 4: bedridden for more than 50 per cent of the day during the past month

* Defined by the CDC as clinical findings of disabling cognitive dysfunction and/or motor dysfunction, interfering with activities of daily living, progressing over weeks to months in the absence of a concurrent illness or condition other than infection with HIV that could explain the findings.

Annex II

Demographic and Health surveys (DHS) and Multiple Indicator Cluster Surveys (MICS) Used to obtain estimates of the number, structure, size and distribution of family households in 36 sub-Saharan African countries* (by source of data and year of survey)

Country	DHS	DHS	MICS
Angola			2001
Benin	1996	2001	
Botswana	1988		2000
Burkina Faso	1998-99	2003	
Burundi			2000
Cameroon	1998	2004	2000
Central African Republic	1994-95		2000
Chad	1996-97		2000
Côte d'Ivoire	1994	1998-99	2001
Democratic Republic of the Congo			2000
Eritrea	1995	2002	
Ethiopia	2000		
Gabon	2000		
Gambia			2000
Ghana	1998	2003	
Guinea	1999		
Guinea-Bissau*			2000
Kenya	1998	2003	2000
Lesotho			2000
Madagascar	1997		2000
Malawi	2000		
Mali	1995-96	2001	
Mozambique	1997	2003	
Namibia	2000		
Niger	1998		2000
Nigeria	1999	2003	
Rwanda	2000		2000
Senegal	1992-93	1999	2000
Sierra Leone§			2000
South Africa	1998		
Swaziland			2000
Togo	1998		2000
Uganda	1995	2000-01	
United Republic of Tanzania	1999		
Zambia	1996	2001-02	2000
Zimbabwe	1994	1999	

* Because HIV prevalence data were unavailable for 2001 and/or 2003 in Guinea-Bissau and Sierra Leone, statistics for these two countries were not included in the estimates of families affected by HIV/AIDS or the analysis related to HIV prevalence rates.

Annex III

Additional tables with correlation analysis and regressions statistics

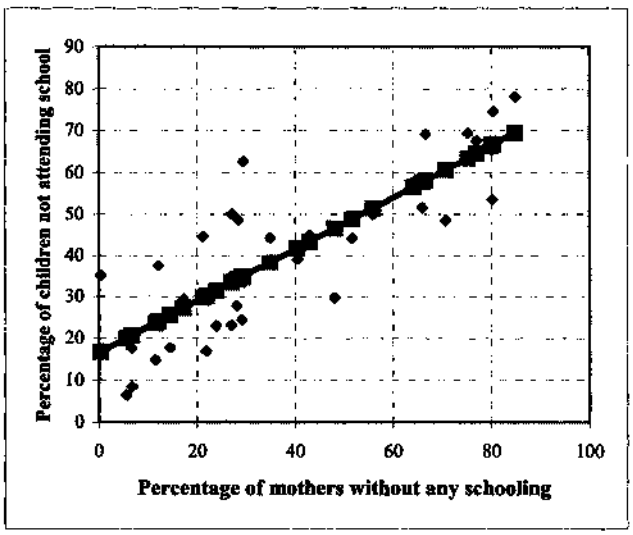
Annex table 1. Total numbers of families and the numbers of families affected by HIV/AIDS, including those affected by the death of a parent or by the AIDS-related suffering or asymptomatic HIV infection of an adult member, 34 sub-Saharan African countries, 2001 and 2003

(*Thousands*)

Country	AIDS-orphaned family households		Families affected by adult AIDS		Families affected by HIV		Total families affected by HIV/AIDS		Total families	
	2001	2003	2001	2003	2001	2003	2001	2003	2001	2003
Angola	27.3	34.3	12.9	15.2	76.7	90.7	116.9	140.2	2 373.1	2 532.2
Benin	6.6	9.1	3.7	4.5	26.8	26.8	37.1	40.5	1 015.4	1 071.0
Botswana	26.1	33.3	24.8	29.7	103.3	99.5	154.2	162.4	277.0	282.5
Burkina Faso	58.3	63.2	22.7	21.4	102.7	113.0	183.7	197.7	1 728.2	1 833.1
Burundi	55.4	67.2	18.8	18.3	73.1	81.5	147.4	167.1	1 146.9	1 220.7
Cameroon	47.3	67.8	32.8	41.0	207.8	208.4	288.0	317.2	2 455.8	2 549.5
Central African Republic	27.2	33.2	16.0	18.8	110.9	107.9	154.0	159.9	560.7	574.8
Chad	20.4	26.8	12.4	13.9	85.7	87.2	118.5	127.9	1 119.4	1 187.8
Côte d'Ivoire	64.7	76.1	35.9	40.0	170.3	188.9	270.9	305.0	2 127.3	2 197.8
Dem. Republic of Congo	195.2	220.5	77.4	72.3	375.3	405.5	647.8	698.3	7 589.3	8 044.5
Eritrea	10.6	14.8	4.7	5.2	22.9	22.4	38.2	42.4	801.0	862.1
Ethiopia	195.8	253.5	72.3	92.9	508.5	573.7	776.6	920.1	12 893.3	13 547.3
Gabon	2.1	3.0	1.8	2.6	13.0	15.6	16.9	21.1	164.2	170.1
Gambia	0.3	0.5	0.3	0.5	2.9	2.8	3.6	3.8	159.6	168.5
Ghana	35.0	43.4	22.2	26.3	121.1	125.4	178.2	195.1	3 402.7	3 554.7
Guinea	6.8	9.6	5.1	6.9	52.9	63.9	64.9	80.3	1 159.1	1 192.7
Kenya	141.4	189.5	129.0	141.9	446.4	416.2	716.8	747.6	5 343.5	5 502.2
Lesotho	23.9	35.6	20.6	26.1	87.0	82.7	131.5	144.4	331.5	332.8
Madagascar	6.3	10.5	3.2	5.2	45.2	61.6	54.7	77.3	3,089.8	3,271.2
Malawi	138.6	175.7	57.0	65.5	327.9	337.5	523.5	578.8	2 338.1	2 434.3
Mali	16.2	20.6	8.0	8.8	57.5	62.8	81.7	92.1	2,031.1	2,155.6
Mozambique	112.5	160.8	69.9	90.8	519.8	526.3	702.2	777.9	3,432.1	3,556.5
Namibia	9.9	17.2	8.0	12.9	18.6	18.0	36.5	48.1	316.3	325.7
Niger	4.3	6.4	2.3	3.1	27.9	34.4	34.5	43.9	1 755.1	1 887.2
Nigeria	376.3	526.1	201.3	250.3	1 328.4	1 365.8	1 906.0	2 142.2	19 787.9	20 826.9
Rwanda	56.1	56.2	16.8	17.0	71.8	79.1	144.7	152.3	1 533.5	1 594.7
Senegal	2.4	3.5	2.2	2.9	15.1	16.0	19.7	22.5	986.4	1 035.0
South Africa	283.7	483.0	250.3	358.7	819.3	795.2	1 353.3	1 636.9	8 402.0	8 517.5
Swaziland	8.7	13.0	9.5	13.7	32.7	27.4	51.0	54.1	126.3	128.6
Togo	9.4	13.9	7.0	8.1	37.7	37.5	54.2	59.5	693.5	726.5
Uganda	247.5	254.5	71.2	57.3	206.7	186.1	525.4	497.9	4 247.5	4 528.4
United Rep. of Tanzania	237.0	297.8	126.5	134.2	558.2	568.2	921.6	1 000.2	6 165.2	6 410.0
Zambia	177.3	194.9	70.2	71.0	280.4	297.1	528.0	563.0	1 838.1	1 880.2
Zimbabwe	252.5	303.2	144.5	157.4	463.3	476.9	860.3	937.5	2 308.6	2 333.0
Total	2 883.2	3 718.7	1 561.5	1 834.8	7 398.0	7 601.9	11 842.6	13155.4	103 699.5	108 435.4

Source: Data for the models and analysis were obtained from the 34 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2002 Revision* (CD-ROM) (New York, 2003) (Sales No. E.03.XIII.8).

Annex table 2. Correlation between children's school attendance and mothers' education in 33 sub-Saharan African countries



Regression statistics

Multiple R	0.828777885
R square	0.686872782
Adjusted R square	0.676771904
Standard error	11.33058459
Observations	33

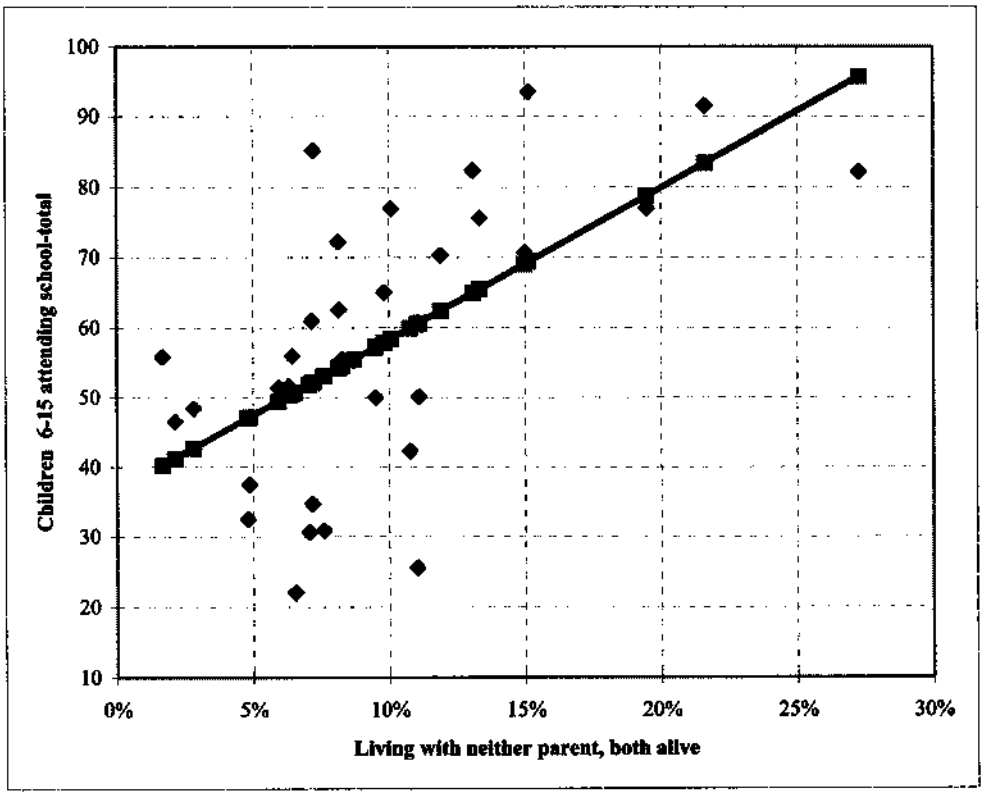
ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	8730.152225	8730.15223	68.0012947	2.5833E-09
Residual	31	3979.846562	128.382147		
Total	32	12709.99879			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	16.47502254	3.635702398	4.5314552	8.1869E-05	9.05995448	23.8900906
Women's education: none	0.624999441	0.075791593	8.24628975	2.5833E-09	0.47042138	0.7795775

Source: Data for the models and analysis were obtained from the 33 national Demographic and Health Surveys and UNICEF-Sponsored Multiple Indicator Cluster Surveys from 1995 through 2003.

Annex table 3. Correlation between school attendance and the living arrangements of children in which both the mother and father are alive but the children live with neither parent, 32 sub-Saharan African countries, circa 1998-2002



Regression statistics	
Multiple R	0.604131
R square	0.364974
Adjusted R square	0.343806
Standard error	15.98926
Observations	32

ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	4 408.062	4 408.062	17.24214	0.000251
Residual	30	7 669.69	255.6563		
Total	31	12 077.750			

	Coefficients	Standard error	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	36.56917	5.792883	6.312776	5.84E-07	24.73854	48.39981
Living with neither, both alive	216.665	52.1787	4.152365	0.000251	110.102	323.228

Source: Data for the models and analysis were obtained from the 32 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003.

Annex table 4. Correlation between school attendance and living arrangements in which children reside with the mother while the father is alive but absent, 32 sub-Saharan African countries, 1995-2003

Regression statistics	
Multiple R	0.754207957
R square	0.568829642
Adjusted R square	0.554457297
Standard error	13.17518974
Observations	32

ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	6870.18345	6870.1835	39.57807	6.1977E-07
Residual	30	5207.568737	173.58562		
Total	31	12077.75219			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 9*
Intercept	30.23217674	4.929666015	6.1327028	9.63E-07	20.164466	40.2998
Living with mother, father alive	177.4445762	28.20560635	6.2911101	6.2E-07	119.841103	235.048

Source: Data for the models and analysis were obtained from the 32 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003.

Annex table 5. Correlation of the incidence rate of families affected by HIV/AIDS with non-orphaned children residing with foster families and women's education in 32 sub-Saharan African countries, 2001-2003

Regression statistics	
Multiple R	0.758306
R square	0.575028
Adjusted R square	0.545719
Standard error	0.00344
Observations	32

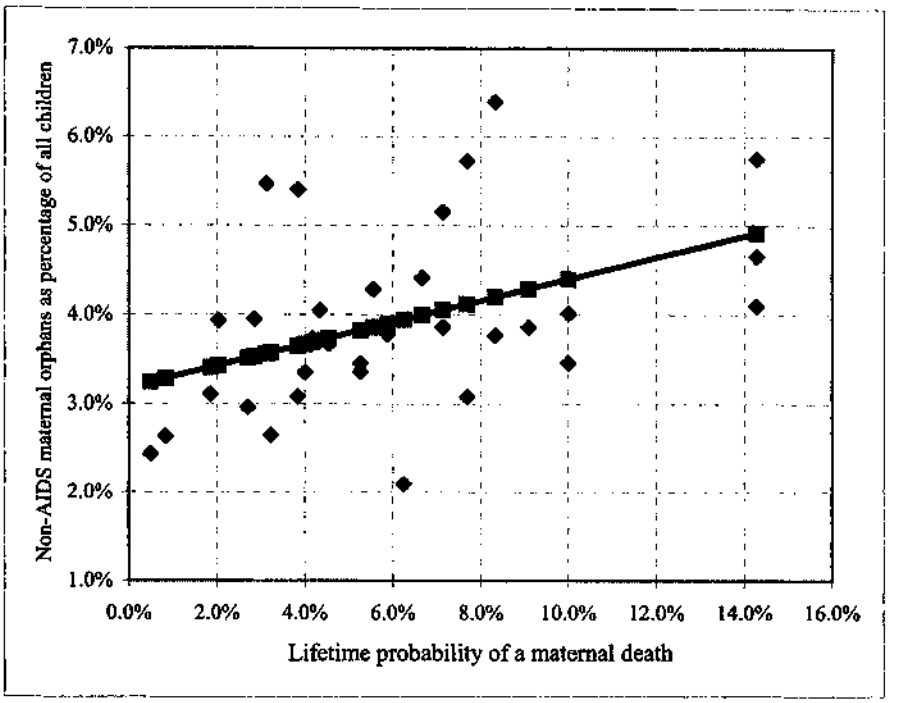
ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	2	0.000464	0.000232	19.61989	4.09E-06
Residual	29	0.000343	1.18E-05		
Total	31	0.000808			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95*
Intercept	-0.00358	0.001572	-2.27624	0.030397	-0.00679	-0.0003
Living with neither, both alive	0.048557	0.012928	3.755881	0.000773	0.022116	0.07499
Women with primary education or higher	6.65E-05	2.67E-05	2.49156	0.018686	1.19E-05	0.00012

Source: Data for the models and analysis were obtained from the 33 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and, United Nations Population Division, Department of Economic and Social Affairs, *World Population Prospects: The 2002 Revision*

Annex table 6. Correlation between the prevalence of non-AIDS maternal orphans and the lifetime probability of a pregnancy related maternal death, 33 sub-Saharan African countries, circa 2000-2002



Regression statistics	
Multiple R	0.4326922
R square	0.1872225
Adjusted R square	0.1610039
Standard error	0.0092709
Observations	33

ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	0.000613746	0.000614	7.140822	0.01190324
Residual	31	0.002664417	8.59E-05		
Total	32	0.003278163			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	0.0318652	0.003198367	9.962973	3.5E-11	0.02534213	0.0383884
Lifetime probability of a maternal death	0.1213824	0.045423595	2.672232	0.011903	0.02874028	0.2140245

Source: Data for the models and analysis were obtained from the Joint United Nations Programme on HIV/AIDS, United Nations Children's Fund and United States Agency for International Development, *Children on the Brink 2004: A Joint Report of New Orphans Estimates and a Framework for Action* (Geneva, New York and Washington, D.C., UNAIDS/UNICEF/USAID, July 2004) available at www.unaids.org, www.unicef.org, or www.usaid.gov. and, UNICEF, UNFPA, World Health Organization, *Maternal Mortality in 2000:Estimates Developed by WHO, UNICEF and UNFPA*, Department of Reproductive Health and Research, World Health Organization, Geneva 2004.

Annex table 7. Correlation between the prevalence of maternal orphans in foster care and women's education in 32 sub-Saharan African countries

Regression statistics	
Multiple R	0.515436
R square	0.265674
Adjusted R square	0.241196
Standard error	0.137877
Observations	32

ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	0.206331	0.206331	10.85379	0.002535
Residual	30	0.570301	0.01901		
Total	31	0.776632			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	0.308203	0.060066	5.131043	1.61E-05	0.185532	0.430875
Women with primary education or higher	0.003047	0.000925	3.294508	0.002535	0.001158	0.004936

Source: Data for the models and analysis were obtained from the 32 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003.

Annex table 8. Correlation between the prevalence of maternal orphans in foster care and total orphan prevalence in 32 sub-Saharan African countries

Regression statistics	
Multiple R	0.3591176
R square	0.1289655
Adjusted R square	0.099931
Standard error	0.1501636
Observations	32

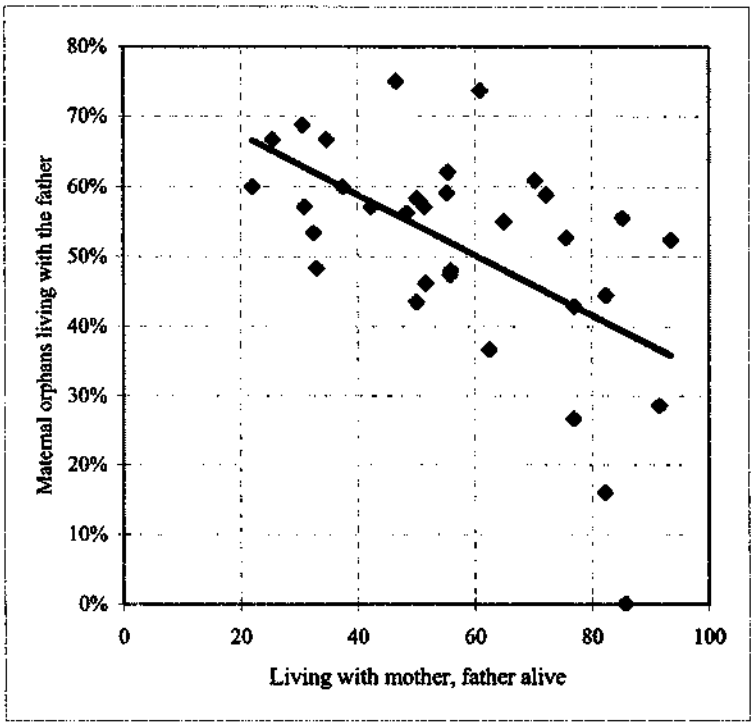
ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	0.10015865	0.100159	4.441803	0.04353382
Residual	30	0.676472862	0.022549		
Total	31	0.776631512			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	0.2884074	0.098841714	2.917871	0.006619	0.08654591	0.490269
Orphans as percentage of all children	1.508445	0.715730995	2.107559	0.043534	0.04672886	2.970161

Source: Data for the models and analysis were obtained from the 32 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003.

Annex table 9. Correlation between maternal orphans living with the father and living arrangements in which children reside with the mother while the father is alive but absent, 32 sub-Saharan African countries



SUMMARY OUTPUT: Living arrangement in which maternal orphans are living with the father and non-orphaned children are living with their mothers, not their fathers

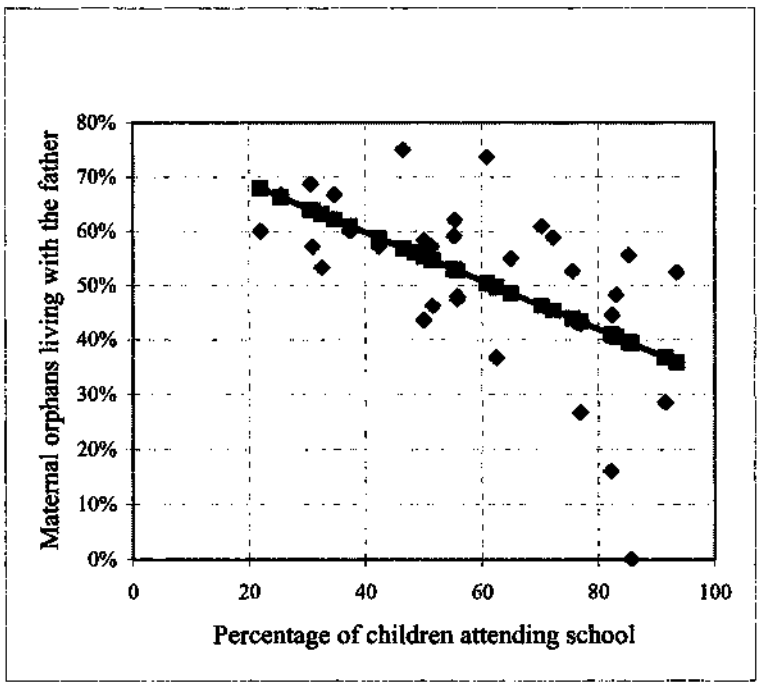
Regression statistics	
Multiple R	0.71512749
R square	0.51140732
Adjusted R square	0.49564627
Standard error	0.11215971
Observations	33

ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	0.408183524	0.408184	32.44753	2.92E-06
Residual	31	0.389973848	0.01258		
Total	32	0.798157373			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	0.72859294	0.042484535	17.1496	2.25E-17	0.641945	0.815241
Living with mother, father alive	-0.0143987	0.002527745	-5.69627	2.92E-06	-0.01955	-0.00924

Annex table 10. Correlation between maternal orphans living with the father and the percentage of children attending school in 33 sub-Saharan African countries



Regression statistics	
Multiple R	0.5786537
R square	0.33484011
Adjusted R square	0.31338334
Standard error	0.13086588
Observations	33

ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	0.267255103	0.267255	15.60534	0.00041927
Residual	31	0.53090227	0.017126		
Total	32	0.798157373			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	0.7772232	0.070501001	11.02429	2.97E-12	0.63343538	0.921011
Percentage of children attending school	-0.0044828	0.001134794	-3.95036	0.000419	-0.0067973	-0.00217

Source: Data for the models and analysis were obtained from the 33 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003.

Annex table 11. Correlation of the annual rate at which families are newly affected by HIV/AIDS with women's education and the living arrangements of children in foster families though both parents are alive, 31 sub-Saharan African countries, circa 1998-2003

Regression statistics	
Multiple R	0.762627
R square	0.5816
Adjusted R square	0.551714
Standard error	0.003423
Observations	31

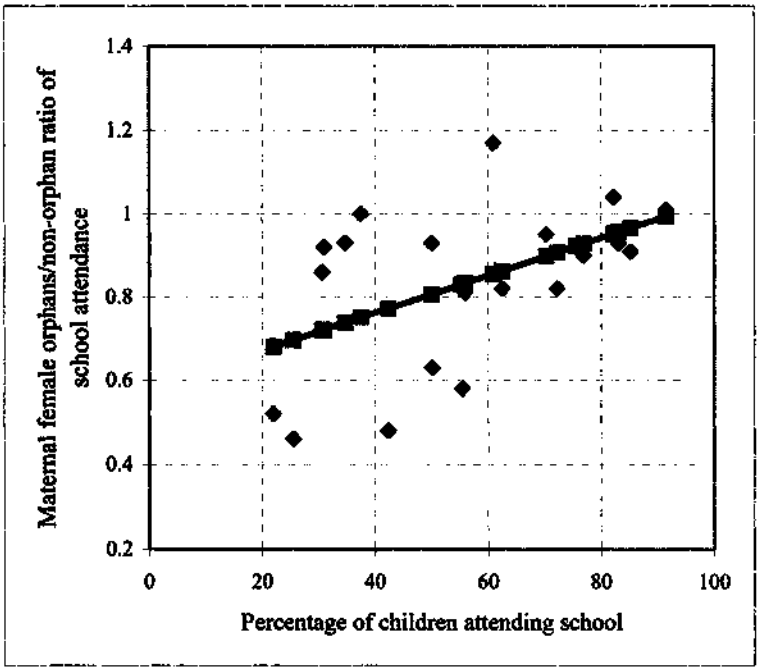
ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	2	0.000456	0.000228	19.4608	5.0383E-06
Residual	28	0.000328	1.17E-05		
Total	30	0.000784			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	-0.00219	0.001498	-1.46554	0.153915	-0.0052629	0.000873
Women with primary education or higher	6.52E-05	2.77E-05	2.35611	0.0257	8.5147E-06	0.000122
Among families with both parents alive, percentage in foster care households	0.023902	0.006747	3.542745	0.00141	0.01008173	0.037721

Source: Data for the models and analysis were obtained from the 31 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1998 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and, United Nations Population Division, Department of Economic and Social Affairs, *World Population Prospects: The 2002 Revision.*

Annex table 12. Correlation between the ratio of orphaned/non-orphaned girls attending school and the overall percentage of children attending school in 23 sub-Saharan African countries



Regression statistics

Multiple R	0.5169463
R square	0.2672335
Adjusted R square	0.2323398
Standard error	0.16321
Observations	23

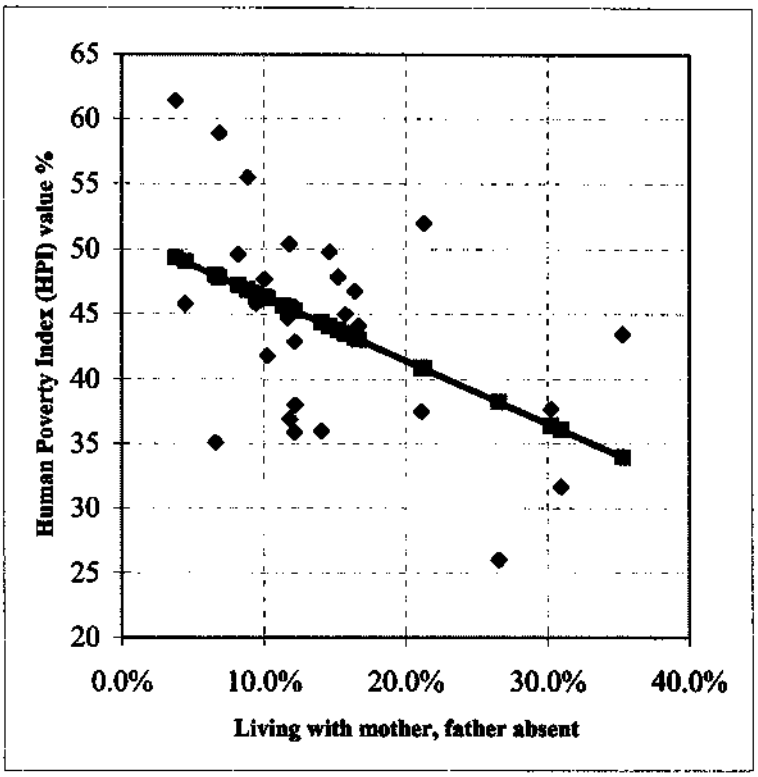
ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	0.204003724	0.204004	7.658515	0.011542
Residual	21	0.559387581	0.026638		
Total	22	0.763391304			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	0.5793649	0.100879564	5.743134	1.06E-05	0.369574	0.789155
Percentage of children attending school	0.0045353	0.001638818	2.767402	0.011542	0.001127	0.007943

Source: Data for the models and analysis were obtained from the 23 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003.

Annex table 13. Correlation of the percentage of people living on less than 1 US dollar per day and the living arrangements in which children reside with the mother while the father is alive but absent, 24 sub-Saharan African countries, 1998-2003



Regression statistics	
Multiple R	0.486197
R square	0.236387
Adjusted R square	0.207017
Standard error	7.134661
Observations	28

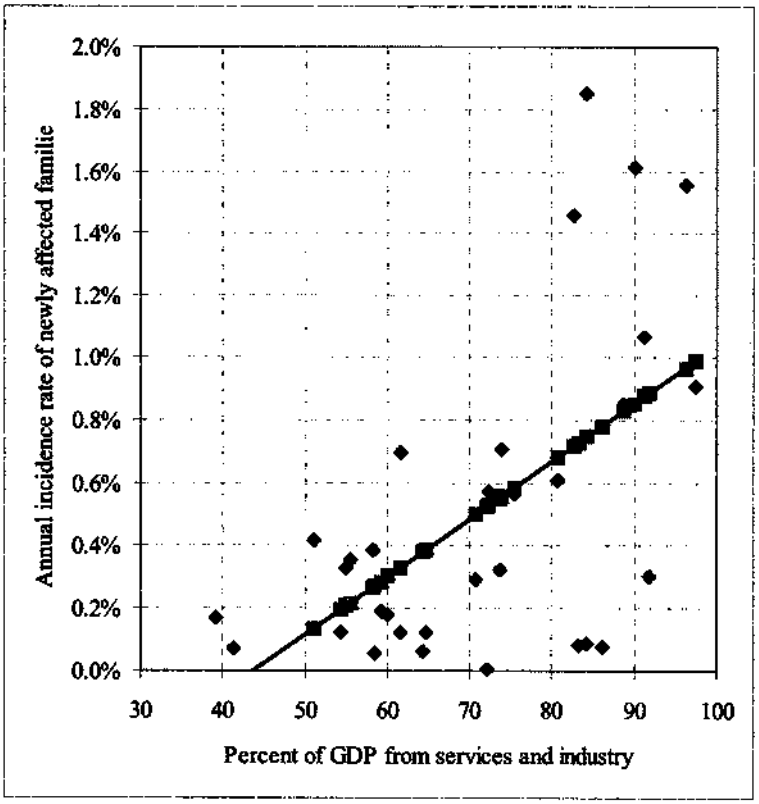
ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	409.7043682	409.7044	8.048666	0.008708997
Residual	26	1323.488132	50.90339		
Total	27	1733.1925			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	51.23546	2.861511252	17.90503	3.83E-16	45.35353371	57.11738
Living with mother, father alive	-48.87727	17.22840354	-2.83702	0.008709	-84.2907884	-13.4638

Source: Data for the models and analysis were obtained from the 28national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; and *World Bank Data & Statistics*, available at http://www.worldbank.org/data/countrydata/ aag.htm

Annex table 14. Correlation of the annual rate at which families are newly affected by HIV/AIDS with the percentage of GDP derived from services and industry in 32 sub-Saharan African countries, 2001-2003



Regression statistics	
Multiple R	0.5705312
R square	0.3255058
Adjusted R square	0.3030227
Standard error	0.0042545
Observations	32

ANOVA

	df	*SS*	*MS*	*F*	*Significance F*
Regression	1	0.000262	0.000262	14.4778	0.0006507
Residual	30	0.000543	1.81E-05		
Total	31	0.000805			

	Coefficients	*Standard error*	*t stat*	*p value*	*Lower 95%*	*Upper 95%*
Intercept	-0.0080227	0.003523	-2.27741	0.03006	-0.0152171	-0.00083
Percentage of GDP from services and industry	0.0001838	4.83E-05	3.804967	0.00065	8.516E-05	0.000282

Source: Data for the models and analysis were obtained from the 34 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2002 Revision* (CD-ROM) (New York, 2003) (Sales No. E.03.XIII.8); and *World Bank Data & Statistics*, available at http://www.worldbank.org/data/countrydata/ aag.htm.

Annex table 15. Correlation of the annual rate at which families are newly affected by HIV/AIDS with living arrangements in which both parents are alive but do not reside with their children and the percentage of GDP deriving from industry and services, 32 sub-Saharan African countries, circa 1998-2003

Regression statistics	
Multiple R	0.663823
R Square	0.440661
Adjusted R Square	0.403372
Standard Error	6.694006
Observations	33

ANOVA

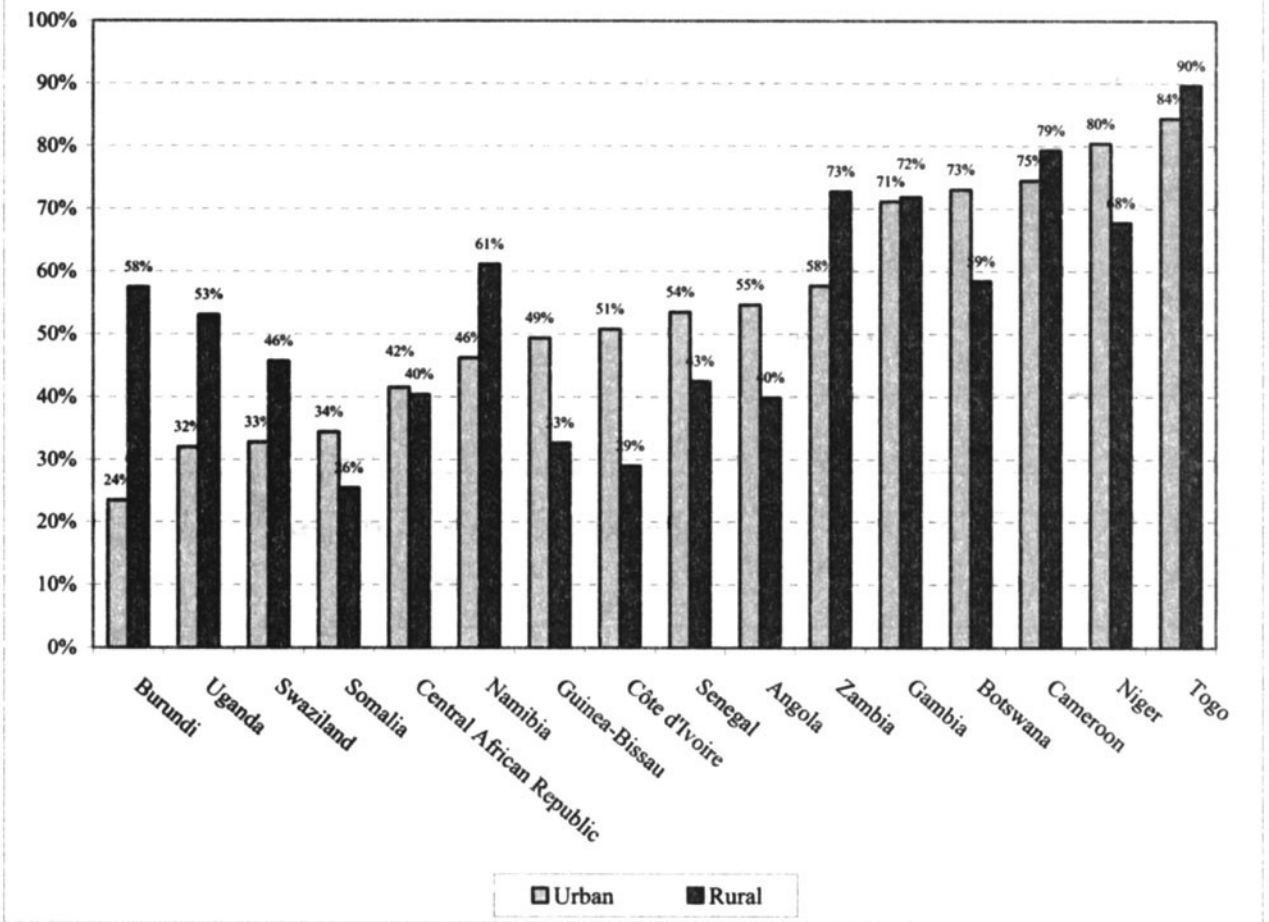
	df	*SS*	*MS*	*F*	*Significance F*
Regression	2	1059.065	529.5324	11.81736	0.000164
Residual	30	1344.291	44.80971		
Total	32	2403.356			

	Coefficients	*Standard Error*	*t Stat*	*P-value*	*Lower 95%*	*Upper 95%*
Intercept	-12.00268	5.53881	-2.16702	0.03830	-23.31442	-0.69094
Among families with both parents alive, percentage in foster care households	0.73851	0.25567	2.88853	0.00712	0.21636	1.26065
Percentage of GDP from industry and services	0.19698	0.08370	2.35338	0.02535	0.02604	0.36792

Source: Data for the models and analysis were obtained from the 32 national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003; UNAIDS, *2004 Report on the Global AIDS Epidemic* (Geneva, June 2004) (UNAIDS/04.16E); and United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2002 Revision* (CD-ROM) (New York, 2003) (Sales No. E.03.XIII.8); and *World Bank Data & Statistics*, available at http://www.worldbank.org/data/countrydata/ aag.htm

Annex IV. Additional Figures

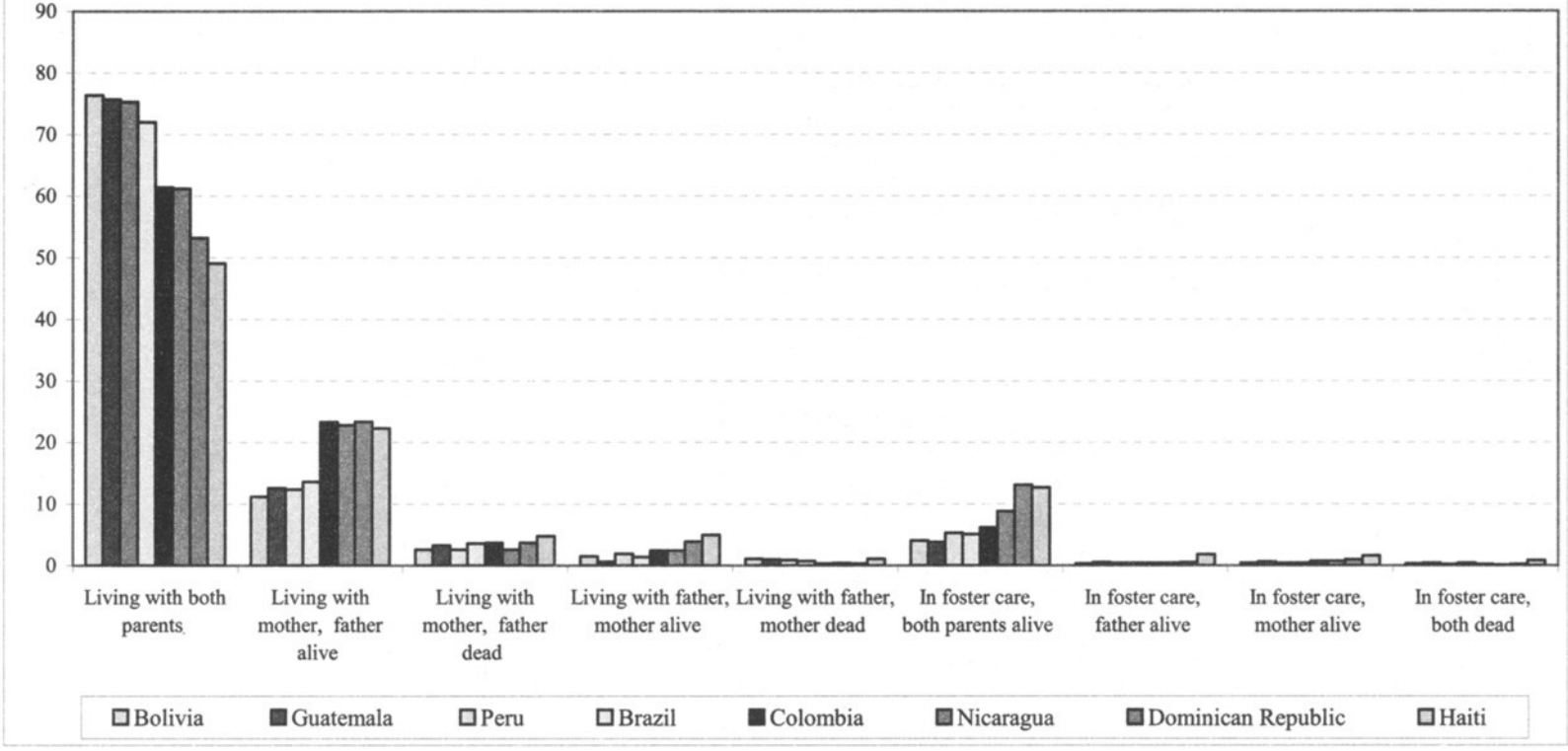
Annex figure I. Percentages of rural and urban women aged 15-49 years who agree with at least one discriminatory statement about persons living with HIV/AIDS, 16 sub-Saharan African countries, 1998-2002



Source: National Demographic and Health Surveys or UNICEF-sponsored Multiple Indicator Cluster Surveys for Angola (2001), Burundi (2000), Botswana (2000), Cameroon (2000), Central African Republic (2000), Côte d'Ivoire (2001), Gambia (2000), Guinea-Bissau (2000), Namibia (2000), Niger (2000), Senegal (2000), Somalia (1999), Swaziland (2000), Togo (2000), Uganda (2001-02) and Zambia (2000), available at http://www.measuredhs.com/.

Annex figure II. Family household living arrangements of children in eight Latin American and Caribbean countries, 1996-2000

(*Percentage*)



Source: Data for the models and analysis were obtained from the eight national Demographic and Health Surveys and UNICEF-sponsored Multiple Indicator Cluster Surveys from 1995 through 2003, available at http://www.measuredhs.com/.