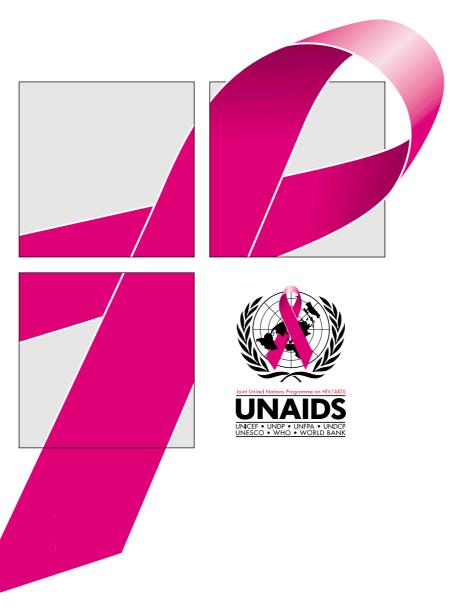
# Guidelines for Studies of the Social and Economic Impact of HIV/AIDS



#### UNAIDS/00.32 E (English original, September 2000)

© Joint United Nations Programme on HIV/AIDS (UNAIDS) 2000.

All rights reserved. This document, which is not a formal publication of UNAIDS, may be freely reviewed, quoted, reproduced or translated, in part or in full, provided the source is acknowledged.

The document may not be sold or used in conjunction with commercial purposes without prior written approval from UNAIDS (contact: UNAIDS Information Centre).

The views expressed in documents by named authors are solely the responsibility of those authors.

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

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by UNAIDS in preference to others of a similar nature that are not mentioned.

Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

# Guidelines for Studies of the Social and Economic Impact of HIV/AIDS

Tony Barnett and Alan Whiteside



UNAIDS Geneva, Switzerland 2000

# Contents

Forword	4
Acknowledgements	5
PART 1. Introduction: The HIV/AIDS Epidemic and its Social and Economic Impact	6
The Purpose of These Guidelines	6
Why Is HIV/AIDS a Special Problem?	7
HIV/AIDS: A Long-Wave Event	8
Stages of Impact: The Long Wave in Action	9
Key Concepts: Susceptibility and Vulnerability	9
The Need for and Purpose of Impact Studies	11
PART 2. Guidelines on How to Do an Assessment of the Social and Economic Impact of HIV/AIDS	12
Identifying the Problem	12
Setting the Terms of Reference	12
The Project Team	13
Sources and Uses of Data	14
A Note on Epidemiology and Demography	14
Surveillance Data	15
Demographic Data	18
Economic Data	19
Social Data	20
Sectoral Data	22
Epidemiological Analysis	23
Assessing the Demographic Effects	24
Projecting the Epidemic	24
Outputs	25
Economic Impact Analysis	26
Macroeconomic Impact	26
Sectoral-Level Impact	26
The Health Sector	28
Institutional Audit	29
Social Impact Analysis	33
Social Structural Impact	33
Social Scale and Location	34
Development Impact Analysis	35
Measuring Development	35
Presenting the Findings	36

PART 3. The Conceptual Framework	38
Impact in General	38
Epidemiology and Demography: The Bases of Any Impact Study	39
Epidemiological Information	39
Demographic Information	39
Social Impact	41
Social Support Systems Explained	41
Social Relations of Production and Reproduction	42
Economic Impact	44
The Macroeconomy	46
Sectoral Level	46
The Firm or Institution	46
Household and Community-Level Impact	47
Timescale	47
Susceptibility and Vulnerability	49
Vulnerability to Impact: Civil Society, Social Capital, and Socially Reproductive Labour	50
Civil Society: Units of Identification, Identity, Consensus, and Conflict	50
Social Capital: Stored Trust, Understanding, and Knowledge	51
Socially Reproductive Labour: The Work of Making Society	52
Conclusion: Some Limitations of Social and Economic Impact Studies	53
There Are No Simple Technical Solutions	53
Technical Annexes	55
Annex A. Methods of Projecting the Epidemic	55
Annex B. Imperfect Data Sets: UNDP and The World Bank	58
Annex C. OECD Development Goals	59
Annex D. Commissioning Socioeconomic Impact Studies: Notes for Government Officials	60
Tables	
Table 1. A Data Collection Matrix	14
Table 2. Checklist for Sector Susceptibility and Vulnerability	27
Table 3. Steps and Processes of an Institutional Audit	32
Table 4. Life Expectancy and Place in the HDI	35
Table 5. Social Impact	43
Table 6. Economic Impact	45
Figures	
Figure 1. HIV Infections, AIDS Deaths, and "Normal" Deaths, South Africa, 1985–2005	8
Figure 2. Projected Levels of HIV Infection in a Hypothetical Country	40
Figure 3. An Epidemic "S" Curve	49

#### **Foreword**

Experience teaches us that stemming the HIV/AIDS epidemic in countries that have a relatively high prevalence of the virus requires a multisectoral approach incorporating prevention, care, and support strategies. Clear and reliable studies on the social and economic impact of the epidemic can encourage the development of effective prevention programmes and prepare countries to face up to the realities of HIV/AIDS.

Many countries, particularly those with a serious HIV/AIDS epidemic, are increasingly adopting strategic approaches to planning and implementation. Specifically, in planning for HIV/AIDS, they are relying on an analysis of their particular HIV/AIDS situation and response in order to define future priorities and to set relevant objectives and strategies. Socioeconomic impact studies can be a key element in informing the analysis and in the overall planning process. However, many impact studies have not been aimed at planning, but have been merely an academic exercise or have provided less than solid data for advocacy purposes.

The present guidelines are intended to place socioeconomic impact studies in the planning process in a systematic way. One of UNAIDS' major motivations for publishing this manual is to encourage countries to include impact information in their strategic planning process. However, UNAIDS would also encourage specific impact studies in sectors such as education and agriculture, where a strong basis for the development of sector-specific alleviation strategies can be formed.

One of the things we have learnt is that plans may be made, but action does not necessarily ensue. In this respect, a strategic planning approach can offer a much-needed dialogue between the planners and researchers and the decision makers. For those impact studies that are undertaken outside the decision-making process, we strongly urge that they include recommendations as to what can be done and that the recommendations are disseminated to the government, NGOs, and donors.

In the present guidelines, the concepts of vulnerability and susceptibility are presented as central elements to identify the focus of the response, including priority setting. Based on lessons learnt, the guidelines list questions that should be considered in preparing and executing impact studies. A background paper by Barnett, Whiteside, and Desmond, "The social and economic impact of HIV/AIDS in poor countries: a review of studies and lessons learnt", is available on the UNAIDS CD-ROM: *Economics in HIV/AIDS planning. Getting priorities right*, July 2000 and the International AIDS and Economics (IAEN) website (*www.iaen.org*). From October 2000 UNAIDS is making available a data base of impact studies conducted in Africa on the UNAIDS web site (*http://www.unaids.org*).

As more studies become available and more experience is collected, these guidelines will become obsolete. UNAIDS is committed to ensuring a collective memory in the important field of the socioeconomic impact of the epidemic and to encouraging countries to share their experiences through the UNAIDS and IAEN websites. To do this we need the cooperation of all the users of these guidelines to forward the agenda – to stem the epidemic and to increase the potential for socioeconomic development in AIDS-ravaged countries.

Joint United Nations Programme on HIV/AIDS (UNAIDS) September 2000

#### **Acknowledgements**

This report was commissioned by Dr Anita Alban of UNAIDS. Preliminary versions were sent for comment to John Stover of the Futures Group International in the United States and Anthony Kinghorn of Abt Associates in South Africa. In addition comments were received from Anita Alban and from Steven Forsythe of the Liverpool School of Tropical Medicine.

Early versions were distributed at two meetings held in Durban: the Health Economic and AIDS Research Division (HEARD), University of Natal, sponsored by USAID, and the Annual University of East Anglia Overseas Development Group/HEARD Policy Research Workshop on the Social and Economic Impact of HIV/AIDS, sponsored by the European Union. Useful feedback was received at both meetings. In addition, the document was posted for discussion on the World Bank's and UNAIDS' International AIDS Economics Network website (www.iaen.org) for several weeks in November 1999. Some useful substantive comments resulted, and we became aware that a number of people were downloading and using the document. We should like to express our gratitude to all who took the time to read and comment on it, particularly Lorri Bollinger, Peter Godwin, and Robert C. Young.

We anticipate that the document will benefit from continuing feedback. However, full responsibility for the content remains ours.

**Tony Barnett** 

Alan Whiteside

# Part 1. Introduction: The HIV/AIDS Epidemic and Its Social and Economic Impact

#### The Purpose of these Guidelines

HIV/AIDS is widespread in much of the developing world. Because it results in exceptional levels of illness and death in the mature adult population, it has many social and economic implications. This manual provides basic concepts to assist in thinking about these implications, together with ideas and techniques for planning responses to the medium- and long-term social and economic impact of HIV/AIDS.

It is not envisaged that these guidelines can be followed in any simple way or that they provide a recipe. They are intended for used by senior researchers as a source of concepts, ideas, and techniques that can be applied in their own setting and to meet their own needs. The guidelines are a beginning point for studies, not an end point. Although this document is intended for those charged with carrying out studies, it can also be used by anyone planning to commission such work.

The document is divided into three parts:

- Part 1 is an introductory section setting out why AIDS is unique and deserving of impact studies;
- Part 2 provides basic guidelines on how to conduct an assessment of the social and economic impacts of HIV/AIDS;
- Part 3 provides a conceptual framework for such socioeconomic impact studies.

In addition there are four annexes:

- Annex A considers some models for developing projections of the epidemic;
- Annex B outlines some of the problems with the data available from UNDP and the World Bank;
- Annex C presents information on OECD development goals;
- Annex D set out some of the issues to be considered by those who commission socioeconomic impact studies.

This manual may be read in conjunction with the background paper "The social and economic impact of HIV/AIDS in poor countries: a review of studies and lessons learnt"\*. This paper discusses the problems and limitations of such studies and puts them in context and also provides some theoretical background to the ideas in this manual.

<sup>\*</sup> Source: Barnett T, Whiteside A and Desmond C, UNAIDS, 2000, available on CD ROM, Economics in HIV/AIDS planning

#### Why Is HIV/AIDS a Special Problem?

AIDS was first recognized as a disease in the early 1980s. Since then it has spread throughout the world. According to the World Health Organization's 1999 *Annual world health report,* it is now the leading cause of death in Africa, responsible for one in five deaths. Globally, it is the fourth most common cause of death. However, there is considerable variation in the pattern of epidemic spread between countries, within countries, and even locally. Consequently there is also variation in the impact of the resulting illnesses and premature deaths. In the richer countries of the world, rates of infection are low, and advances in treatment mean that people can live with AIDS, although for how long and in what state of health is still unclear. The burden of the epidemic falls on the world's poorer countries and also on poorer communities in some richer countries.

AIDS is caused by the human immunodeficiency virus (HIV). This virus is transmitted via human body fluids; globally most infections occur through sex between men and women. The virus attacks the immune system and ultimately makes it ineffective. Most people die of infections or cancers against which they might well have defended themselves were it not for their compromised immune systems. There is a strong link between HIV and tuberculosis. Many people are infected with TB without the disease being active; however, once HIV infection occurs, it allows the TB to emerge. Consequently, TB is one of the major opportunistic infections and killers of HIV-infected people.

Because most HIV infections are the result of heterosexual intercourse, the disease tends to affect people in the age group that is broadly defined as "sexually active" – between 15 and 50 years (although this is not to say that there are not infections below and above this range). The significance of this epidemiological characteristic is that the age group most susceptible to infection is also the most economically and socially active. Under normal circumstances, people in this age group are also least likely to be ill and/or die. The issue of the social and economic impact of the HIV/ AIDS epidemic stems from the unusual rates of severe illness and premature death that it produces in this age group.

HIV infection is not an immediate death sentence. Depending upon individual constitutions, rates and types of ambient infection, living conditions, diet, and other factors, an infected person may have several productive and healthy years before starting to fall ill (developing AIDS). Although no one is certain how long people can live with HIV, the range is estimated at, on average, five to eight years in poorer countries, possibly many more in richer countries. Eventually the person will begin to experience periods of illness that increase in frequency, duration, and severity until death. Many opportunistic infections and diseases associated with AIDS can be treated (or prevented) at relatively low cost, thus prolonging life. Recently developed antiretroviral therapies may reverse or slow disease progression, but these are expensive: proven therapies cost \$8,000 to \$11,000 per person per year for the drugs, and this amount does not include the cost of testing and of clinical oversight of treatment regimes. (There are some cheaper options, but it is unclear how effective these are as therapies, or how cost-effective they are.) The therapies are complex to administer and are most effective when the person receiving treatment has a good diet, healthy living conditions, and a stress-free environment. These conditions and the requisite financial resources are least likely to be available to the poor.

#### HIV/AIDS: A Long-Wave Event

Because the virus is slow-acting, with an incubation period of many years, an HIV/AIDS epidemic is a long, slow event. By the time that even a few people with AIDS are recognized by clinical services (or the community), many more exist whose condition has not been diagnosed or observed; there are even more who are well but infected with the virus. In short, a major problem is that once significant numbers of people begin to fall ill and to die, the HIV epidemic will already be far advanced. This is well illustrated by Figure 1, which shows the epidemic in South Africa. In 1999 there were an estimated 2,947,000 HIV infections in that country but "only" 97,000 AIDS deaths. The new HIV infections recorded in 1999 will develop into AIDS cases and deaths over the next five or so years. It is projected that by 2005 there will be about 383,000 AIDS deaths in South Africa. Nepal is an example of a country in which the epidemic is at an earlier stage. There, in early 1999 about 1,209 people had been recorded as infected with HIV. This suggests that approximately 25,000 people might be infected countrywide, but few people had actually been diagnosed as sick with AIDS.

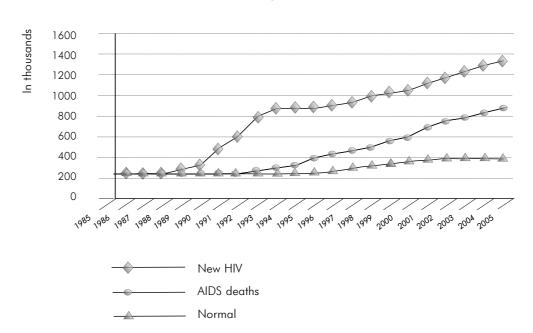


Figure 1. HIV Infections, AIDS Deaths, and "Normal" Deaths, South Africa, 1985–2005

Source: Provided by the AIDS Research Division of Metropolitan Life, Cape Town, South Africa

#### Stages of Impact: The Long Wave in Action

Once HIV begins to spread in a society, certain consequences are inevitable, although initially they are invisible. The extent of these consequences and the speed with which they occur will depend on the effectiveness of prevention programmes and the degree to which the society is willing and able to plan for the impact.

The following stages of impact apply to an HIV/AIDS epidemic:

- Stage 1: No people with AIDS are visible to medical services; some people are infected with HIV.
- Stage 2: A few cases of AIDS are seen by medical services; more people are infected with HIV.
- Stage 3: Medical services see many people with AIDS. There is some awareness among policy-makers of HIV infection and AIDS. The incidence of reported TB cases increases.
- Stage 4: The number of AIDS cases may threaten to overwhelm existing health services. There is widespread awareness among the general population of HIV infection and AIDS.
- Stage 5: Unusual levels of severe illness and death in the 15–50 age group produce coping problems, a significant number of orphans, and the loss of key household and community members. TB is a major killer.
- Stage 6: Loss of human resources in specialized roles in production and in economic and social reproduction decreases the ability of households, communities, enterprises, and even districts to govern, manage, and/or provision themselves effectively. These difficulties elicit various responses, which may include creative and innovative ways of coping or the failure of social and economic entities. Both types of response may be observed in the same country, region, enterprise, or household.

Although some countries have reached Stages 4 or 5, little evidence exists that any country as a whole has moved beyond that level. At the subnational level, however, some regions and communities that reached Stage 5 within the last decade may be reaching Stage 6. There is anecdotal evidence at the subnational, community, and enterprise level of Stages 5 and 6.

#### Key Concepts: Susceptibility and Vulnerability

These guidelines focus on two important concepts: susceptibility and vulnerability.

Susceptibility refers to the individual, group, and general social predisposition to infection. This concept may be applied at any level, from an entire society or country to a household. Thus, individuals, nations, and societies are more or less susceptible to infection, and the speed and extent of the spread of HIV will be determined by the susceptibility.

Vulnerability refers to those features of a social or economic entity that make it more or less likely that the excess morbidity and mortality associated with disease will have adverse impacts upon that entity. Thus, families, communities, and societies will be more or less vulnerable to the impact of increased morbidity and mortality.

The distinction is made between the two terms because a society may be susceptible but not vulnerable. A study of social and economic impact should show clearly whether and how each level – subject area, social unit, social group, institution – contributes to susceptibility and whether and how it is vulnerable to the impact of the epidemic. Where vulnerability is indicated, a policy option or options should, as far as possible, be suggested for dealing with this.

### The Best Outcome of Impact Studies – Self-Defeating Prophecies

- Prevention requires that people change their behaviour when they cannot see any reason to do so. This reluctance may result in distorsion and misunderstanding of prevention messages.
- Planners and policy-makers are asked to plan for something which cannot yet be seen, which will evolve over a period of years, of which no one has experience, and for which there are few, if any, precedents.
- Successful planning for prevention and/or impact will mean that the
  problems that people were warned about did not happen. Some people
  may question whether the expenditure of money and effort was worth
  while.
- Because all new infections cannot realistically be prevented, people may feel that prevention is failing, even when it could be having a significant impact.

One of the common responses to the epidemic has been denial that there is a problem. This response has occurred at the individual, communal, and national level. The problem of denial is even greater with regard to impact because it is quite hard to demonstrate.

#### The Need for and Purpose of Impact Studies

One of the most important messages of this document is that, if consultants and researchers want to see the socioeconomic impact of HIV/AIDS, they have to look for it. It is particularly hard to detect impact that is not measured by existing and conventional economic instruments.

Why is there the pressure and need to produce socioeconomic impact studies? Often the first reaction of a country faced by the epidemic reaching Stage 3 is to commission such a study. The arguments for the studies are:

- If there is a measurable or predictable impact, then people can be convinced of the problem. Showing impact becomes an important tool for *advocacy* encouraging politicians, leaders, and policy-makers to engage in prevention. If the effects of an increase in illness and death can be shown, then the need for prevention will be clear.
- If the epidemic will have an impact, it is necessary to know its location, scale, and form to begin *planning* for it. For example, the Health Ministry needs to look at increased demand, and a private company might assess the effects of illness and death on the availability of skilled employees and on the level and type of employee benefits.

Impact studies have a dual purpose. They provide the rationale for both prevention and mitigation. As was noted above, for countries in the early stages of the epidemic there is a paradox: if advocacy is successful, prevention may be more effective and reduce impact, and people may then regard the warning as mere scare tactics. Impact studies should be able to accommodate this tendency and not produce overly alarmist scenarios. In countries with more advanced epidemics, there is no doubt that there will be an impact; the challenge is to predict and mitigate it.

One of the major problems with many impact studies is that they are commissioned, carried out, and then shelved. This is partly because most are "standalone" studies – that is, they look at one aspect of the impact and are not part of a strategy to respond. Ideally studies should be part of, or feed into, such strategies.

# Part 2. Guidelines on How to Do an Assessment of the Social and Economic Impact of HIV/AIDS<sup>1</sup>

#### Identifying the Problem

The first problem that faces someone undertaking a social and economic impact assessment is that impact has not yet been very detectable, much less catastrophic, at the macro level. For this reason, analysis of impact requires methods that detect it at the meso (middle) and micro levels. The second problem is that there are two sets of people who form the audience for the report and may also be among those responsible for commissioning it: those who doubt that a problem exists and those who think that catastrophe lies ahead. Both of these groups will be disappointed, and it is the consultant's task to modify their expectations in discussion concerning terms of reference. The actual situation is that the impact will be:

- detectable, but only if the correct instruments are developed and used;
- located in certain social, economic, and spatial groups and areas, some of which may have little political influence or importance and therefore may not attract attention; and
- felt slowly over a long period.

These points must be drawn to the attention of those who commission the work.

#### Setting the Terms of Reference

It is very important that the terms of reference recognize that, within the normal period allowed for such work, it will be unlikely that primary data can be collected. However, one of the outcomes of the impact study might be to suggest additional studies that are needed, which could include primary data collection. It is also important to recognize that a single study cannot provide a detailed and quantified account of the impact of the epidemic. What it can do is:

- use existing data insofar as these allow the consultants to form some picture of impact;
- indicate some possible scenarios of HIV spread and numbers of illnesses and deaths, and make assessments of their relative likelihood;
- suggest the particular population subgroups most vulnerable to impact;
- assess and balance anecdotal accounts of current impact with other data and experience;

An example of an early attempt to undertake such a study at a national level can be found in Tony Barnett and Alan Whiteside, The social and economic impact of HIV/AIDS in Ukraine (Kiev, British Council, 1997). This study may be found on the web at http://www.britishcouncil.org/ukraine/english/governance/aids/index.htm.

- obtain information on current coping mechanisms and capacity;
- suggest, on the basis of appropriate consultation, what areas require policy development, decisions, and action over what time period;
- propose additional studies and draft terms of reference for these.

A crucial first step is to establish the immediate purpose of the assessment. Is it primarily for advocacy purposes, to provide detailed information for planning, or both? This will guide both the work and the reports/presentations and allow the consultants to make appropriate proposals and draw accurate budgets. One way to establish the purpose is to be clear about who is the target group for the work.

#### **Expectations and Realities**

The experience of one African country may be instructive in terms of the need to establish the purpose of the study. A key government ministry requested a number of studies into the impact of AIDS. These took over a year, from commissioning the work to presenting draft reports, and got bogged down on details of the study. The expectations of what could be produced did not take into account the complexity of the problem, nor was it clear that everyone in government had "bought into" the process of carrying out the study.

These elements should have been addressed at the outset.

#### The Project Team

A social and economic impact study must be overseen by an interdisciplinary team of senior researchers and administrators. It is positively *not* a project to be undertaken by junior people. It requires strong political and administrative support if it to be completed successfully and have the desired outcome of influencing opinion and enabling a society to cope with the medium- and long-term impact of HIV/AIDS. Such a study is not a small undertaking, and it is likely to take several months to complete.

Ideally, the executing team should consist of at least the following: an epidemiologist and/or demographer, an economist, and a sociologist/social anthropologist who is used to working in relation to policy. Ideally these people should be engaged full-time; in reality this may not be possible, in which case sizeable allocations of their uninterrupted time should be assured. Additional inputs may be required from specialists with expertise in agronomy, rural development, forestry, mining and industrial production, transport, and gender. Whichever disciplinary specialists are involved, it is vital that they are able and willing to work across disciplines and in relation to communities and activists.

#### Sources and Uses of Data

A useful first stop for data collection may be the official government website for a particular country. These sites often contain a wealth of information.

Data are presented to support the findings and recommendations of the studies. As well as background information the study should be looking for data that informs the analysis of the susceptibility and vulnerability of the society, sector, or groups in it. In particular the study will need to establish trends. As noted above, impact may be hard to see because:

- 1. The epidemic has not developed enough for the effects to be felt.
- 2. The right things are not being measured.
- 3. It may not be possible to ascribe trends specifically to HIV/AIDS.<sup>2</sup>

It may be useful to construct a table for data collection (see the example in Table 1). This table would set out the types of data that are required, why the data are needed, and where they might be found.

Data required	Reason	Objectives	Source
1. Demographic	Core to projections	Basic information and impact assessment	Government statistics office
1.1 Population size	For projections	Feed into projection	As above
1.2 Population structure	For projection and analysis	Etc.	Etc.
Etc.	Etc.	Etc.	Etc.

**Table 1. A Data Collection Matrix** 

#### A Note on Epidemiology and Demography

Epidemiology is the study of the distribution and progression of illness or other health-related events in a population. In the context of this manual, it concerns the distribution and progression of infection and illness in human populations. Typically, epidemiology shows the spatial and social location of infection and illness. Such information should be able to show who is infected and/or ill, where they are, and how many such people exist at any particular time. It should also be able to show changes over time in these characteristics and thus the progress and development of

<sup>&</sup>lt;sup>2</sup> For example, the death rates may be rising, but AIDS is not identified as the cause, or child mortality may appear stable if improvements in nutrition, clean water, and health care mask the increased deaths due to AIDS.

the epidemic. For example, epidemiological studies should indicate the age and gender distribution and the geographical location of people who are HIV-positive or who have developed AIDS. Such statistical data then provide indications of possible routes of infection, the potential development of an epidemic, and the social and spatial location of the disease over a defined time period. An epidemic of an infectious disease typically develops geometrically: a small number of cases lead to a larger number of cases, followed by a very rapid increase until a plateau has been reached where most of the susceptible individuals have been infected. The geometric curve that an epidemic follows is known as a sigmoid or "s-curve" from the typical form it assumes.

Demography is concerned with basic life events of individuals — birth, ageing, and death. These individual events are used to provide accounts of the structure of a population, in particular the numbers in each defined age cohort, the dependency ratio, life expectancy, age-specific death rates, and changes in these variables. Such information can then be used to make projections as to how the structure of the population may change over a given time period.

#### Surveillance Data<sup>3</sup>

Surveillance data are usually drawn from official sources. The two most common types of data are:

- 1. AIDS case data that is, the number of AIDS cases by age, gender, and transmission category. The value of such data is limited because, in most countries, only a small number of cases reach official reports.
- 2. HIV data drawn from surveys of specific groups. Typically these will include blood donors, people who attend sexually transmitted disease (STD) clinics, people with TB, and women who attend antenatal clinics (ANCs). Women who attend ANCs provide the most useful data at present: such data are usually based on surveys done at regular intervals and have fewer and more predictable biases than other data.<sup>4</sup>

Until recently the only way to test for HIV was by using blood samples, which made carrying out population-based sample surveys very difficult. The development of saliva testing will result in a wider range of data becoming available. ANC data,

<sup>&</sup>lt;sup>3</sup> A literature search of published articles, as well as abstracts from various conferences, can be performed free of charge at http://igm.nlm.nih.gov.

<sup>&</sup>lt;sup>4</sup> It is very important to remember that all data are subject to bias. When examining HIV data, one should assess bias by considering the following issues: (1) How representative of the general population is the group for which data have been collected? Typical groups in decreasing representativeness are: women who attend antenatal clinics, blood donors, commercial sex workers (CSWs), and injecting drug users (IDUs). (2) What differences might exist between urban and rural prevalence rates? Data are usually collected from urban areas, and rural rates are often lower than these. (3) HIV infection suppresses fertility, which means that prevalence data derived from women who attend antenatal clinics may underrepresent prevalence. (4) There are differences in male-female ratios at various points in the epidemic: >1 for early, 1 or less for later once again leading to selectivity in the HIV prevalence data obtained from women who attend ANCs (depending on the stage of the epidemic).

while they have their limitations, provide the opportunity to collect data on a sexually active group of adults. Also, as blood samples are taken from pregnant women for a range of tests, some can be used for anonymous unlinked screening.

#### **Note on Antenatal Clinic Data**

Recent population-based studies have shown that ANC data provide a good estimate of HIV prevalence in adults aged 15 to 49. When the epidemic is modelled, the data are manipulated to produce estimates of prevalence for all adults and for the population at large.

ANC data are appropriate when the epidemic is largely heterosexually driven, as is the case in Africa and most of Asia. It may not be appropriate where the majority of cases are injecting drug users or men who have sex with men. In these situations, other data will need to be collected.

For an excellent discussion on data sources and their value see "Reaching regional consensus on improved behavioural and sero-surveillance for HIV: report from a regional conference in East Africa", UNAIDS Case Study, June 1998, UNAIDS Best Practice Collection, <a href="http://158.232.21.5/wsite/00\_core\_frame.html">http://158.232.21.5/wsite/00\_core\_frame.html</a>.

#### **Note on Terminology**

The most common surveillance data terms are prevalence and incidence. Prevalence measures the number of cases at a given time; in the case of HIV it is given as a percentage. Thus, in Swaziland 31 per cent of women attending ANC clinics are HIV-positive. Incidence measures the number of new occurrences of a disease. Prevalence is the stock of HIV infections; incidence is the flow.

It is very difficult to measure HIV incidence because we don't know when people are infected. This is unfortunate because these data would be most helpful in measuring the impact of prevention efforts. However high incidence may occur when prevalence has levelled off, if many people are dying and being replaced by new infections.

The first source for surveillance data should be the national AIDS control programme of the country under study. Such programmes should have all available information on AIDS cases and sero-survey data. If such data exist, they should be used to obtain as much detailed information as possible. In addition, any subsequent projections made on the basis of the data should be noted. If annual reports of the AIDS control programme are available, the researcher should assemble or gain access to as many years as possible to gain a perspective of the epidemic. It is important to note carefully what categories of people from what regions and districts of the country are being used as the main source of information, and how the data are being collected.

When the main outline and method of the published official figures have been established, the researcher should see whether there are any more detailed unpublished data that could be of use. It is important to note which geographical areas and social groups are most likely to be absent from the official figures, and to consider how this might influence the official view of the epidemic. Some thought should be given to why and how the data came to be constructed in the way that they were. What does that construction reveal about biases and lacunae in the processes of data production? Does this suggest anything about how the next stages of the impact analysis need to be approached? It is also important to remember that aggregate data, even down to the regional and district levels, may not reflect particular communities, which may be much better or worse than the average.

After it is clear that no further detailed data about the epidemic can be obtained from this source, other possible sources that have not contributed to the official statistics should be considered. Possible sources of further information are: genito-urinary and other medical practitioners, medical officers in major enterprises and the armed forces, insurance companies, blood banks, major district and general hospitals, and mission hospitals. The data from these sources will be biased in various ways and should be treated with caution.

Once the HIV data have been obtained, the consultants can determine the stage of the epidemic in the country being studied. It is extremely unlikely that the study would have been commissioned if alarm bells were not ringing, which probably means the epidemic is at the generalized stage (see "Epidemic Stages" box). The stage of the epidemic will affect both impact mitigation and prevention strategies.

#### **Epidemic Stages**

- Low level: HIV is less than 5 per cent in all known subpopulations presumed to practise high-risk behaviour for which information is available.
- Concentrated: HIV prevalence is above 5 per cent in one or more subpopulations presumed to practise high-risk behaviour, but among women attending urban antenatal clinics it is still below 1 per cent.
- Generalized: HIV has spread far beyond the original subpopulation presumed to practise high-risk behaviour, and this subpopulation is now heavily infected. Prevalence among women attending urban antenatal clinics is 1 per cent or more.

Source: UNAIDS, USAID, IMPACT, "Meeting the behavioural data collection needs of national HIV/AIDS and STD programmes: a joint IMPACT/FHI/UNAIDS workshop. Report and conclusions", May 1998, p. 22

An overview of surveillance data for most countries can be obtained by visiting the UNAIDS website, *http://www.unaids.org*, and using the searchable database. This will provide basic information about seroprevalence levels and numbers of AIDS cases as well as a variable amount of detail depending on the data reported by national bodies to UNAIDS. Much of this information is at least a year and possibly two years old. Another source of background information is the United States Census Bureau. Its website, *http://www.census.gov*, also permits a search for information by country. It is

unlikely that this site will have data not available in the country being studied, but it may have useful compilations, can provide an overview, and can show data from neighbouring countries.

It may be of value to assess the experience of neighbouring countries. Those that are further ahead in the epidemic may provide indicators of what could happen in the country being studied. Particular attention should be paid to border areas. It is possible that there may be significant epidemics here that are not picked up in national data. For example, if data were available for the "Golden Triangle", and this were a country, it would have one of the most serious epidemics in Asia. Instead the data are lost in the national epidemics of India, Thailand, Myanmar, and China.

#### Demographic Data

Demographic information is necessary for both the projection of the epidemic and an understanding of where it might have impact. There are four common sources of demographic data:

- official census and population surveys and vital registration information
- demographic and health surveys
- international agencies
- reports by academic demographers.

Official census and population surveys are the best sources of data but will be limited in their usefulness by how long ago they were done, the quality of the material collected, and the degree to which the data have been analysed. Insofar as it usually takes about four years for any useful analysis to be produced by census departments, it is probable that the most recent materials available will be about five years old. These will be perfectly satisfactory for purposes of projecting the epidemic using the programmes described below. Vital registration - that is, information collected by governments about births and deaths - is another important source. It will vary in quality depending on national systems in use and even the quality of local and regional administrations. However, it should be examined for information about numbers and causes of deaths. At the same time, causes of death will often be no real indicator of AIDS, as these deaths are often reported by the immediate cause of death, such as tuberculosis or pneumonia. An additional problem is that in many countries the births and deaths of only a small fraction of the population are reported. The value of such data will be to track trends in terms of numbers of deaths, and the age and gender of those dying.

The United States Census Bureau website, provided above, has information about the demography of a range of countries. The address <a href="http://www.census.gov/main/www/stat\_int.html">http://www.census.gov/main/www/stat\_int.html</a> leads to the official statistical bureaux of many, but not all, countries.

Demographic and health surveys are undertaken by Macro International Inc. of Calverton, Maryland, USA, in cooperation with local bureaux of statistics and offices of population and census. Macro International has a website at <a href="http://www.macroint.com/dhs">http://www.macroint.com/dhs</a>. Its pages at <a href="http://www.macroint.com/dhs/indicatr/">http://www.macroint.com/dhs/indicatr/</a>

*datasearch.asp* provide information about the demography and health of the countries where the company has done surveys.

International agencies are a source of increasingly important data – those on life expectancy and on infant and child mortality. The most up-to-date and regular sources of these data are the annual reports produced by the United Nations Development Programme (UNDP), UNICEF, and the World Bank. All seem to use their own demographers to calculate these figures. (See Annex B for a discussion of some of the limitations of UNDP and World Bank demographic and development data.) It is on these indicators that the first "official" impact is seen. The websites are: <a href="http://www.undp.org">http://www.undp.org</a> (UNDP), <a href="http://www.worldbank.org">http://www.undp.org</a> (World Bank), and <a href="http://www.unicef.org">http://www.unicef.org</a> (UNICEF).

Reports by academic demographers can be found in professional journals. Incountry as well as international journals should be explored. International journals include: Journal of Demography, Population and Development; Population Studies; and Health Transition Review.

Epidemiological and demographic data are required in order to make projections of the impact of the epidemic. The most commonly used (and the most accessible and user-friendly) projection model is the Spectrum model developed by the Futures Group International. (This model is discussed in more detail in Annex A.)

#### **Economic Data**

The purpose of economic data is to provide a profile of the country or region and assist in identifying areas of susceptibility and vulnerability. The collection of such data should be reasonably simple. The key is their interpretation.

Basic economic data will include information on the size and structure of the national or regional economy. In particular, the consultants should identify the key sectors. It is also important to have an idea of how the economy works, especially in relation to external factors — is it dependent on a few commodities, heavily in debt, or dependent on aid? Information on the labour force should include participation rates, levels of unemployment, skills profile, educational level, age, and gender. If data are available for several years, the consultants should try to identify trends.

Inequality and mobility are indicators of susceptibility – that is, they are key to increasing people's risk of HIV infection. In order to assess these elements it is necessary to look at how income and wealth are distributed (the Gini coefficient is a key indicator of income distribution), but it is also important to identify groups who are relatively wealthy and relatively poor. For example, in a society where there are few income-earning opportunities, and these are primarily the preserve of men, it is likely that commercial sex will be one of the few survival strategies open to many women. Mobility is important because it creates the environment in which sex with a non-regular partner is more likely to occur. In this case there may be indicators of labour mobility both within areas or countries and across borders. The rates of urbanization may also indicate susceptibility.

In identifying *indicators of vulnerability* one is looking for areas where the loss of labour or the increased demand for services resulting from increased morbidity and mortality may be crucial. These will include sectors that depend on skilled or experienced labour. The relevance of experience should not be missed. A good example is the gold-mining industry in South Africa. Although the gangs of miners are

theoretically unskilled, they have to work together in a dangerous environment and productivity is dependent on their working as a team with one or two key people. Another area of concern may be the civil service, particularly the range and condition of services provided by, and the employment entitlements of, civil servants. The likely demand for increased services as a result of the epidemic will affect mainly the welfare sectors, in particular health and social service. It is therefore important to know the provisions of these sectors and how they are likely to be affected.

The first source for economic data should be the Ministry of Finance/Economic Planning and central statistical offices. Secondary sources will be the central bank, commercial banks, and major donor agencies. Development agencies usually collect data, and it would be worth checking what they have. In particular the UN has established AIDS theme groups in many countries. The World Bank and UNDP are members of these groups, and information can be sought through them. The Economist Intelligence Unit produces country reports and country profiles for all the countries of the world, but access to these is expensive. The Unit may provide one or two in exchange for a copy of the impact report. (Economist Intelligence Unit, 15 Regent Street, London SW1Y 4RL, UK. Email: <code>london@eiu.com</code>; website: <code>www.eiu.com</code>.).

#### Social Data

Data about society are scattered in many places, ranging from newspapers and government reports to published books and academic journals. They are also contained within people's minds: interview and focus group information should not be forgotten even though it is unreasonable to expect to be able do a large amount of original investigation as part of an impact study. Governments and international agencies (particularly the latter) often commission reports that summarize considerable amounts of existing and perhaps hard-to-find information.

It is important to select only those data that are of relevance for understanding the actual and potential impact of the epidemic. This selection process is not, however, straightforward. What, for example, is the primarily interest? The main issues for which data need to be collected can be summarized, together with some explanatory comments, as follows.

• Households: This basic unit of most systems of immediate social support may take many forms and differ markedly from culture to culture. In addition, the very term "household" may be misleading, because many people's arrangements involve complex networks of support between people who are related to each other in a wide variety of ways. It is important to know about the range and types of households and about the different structures of relations, in particular the types of intra- and inter-household transfers of resources. This information permits assumptions about the numbers of each type of household and the probable directions of change in relation to HIV/AIDS.

Two household-related groups about whom information needs to be sought are orphans and the elderly.

- Orphans will become more common. Their numbers may adversely affect established coping mechanisms in households and extended households.
- The elderly may be left without the support of their adult children and may therefore experience extreme poverty and social isolation.

Particular information should be sought about levels and standards of life and of welfare in different sets and subsets of households.

• Gender relations: It is essential to collect data relating to gender issues. These data should be as detailed as possible and indicate clearly, where possible, norms in relation to power both inside and outside marriage; changes over time; directions of change; locational differences; differences by income and occupation; differences by ethnicity, religion, and other major features of social differentiation (see Social differentiation below); and core components of the social and cultural construction of gender. Some of the most commonly available data on gender relate to the male-to-female ratio of AIDS cases. While these data can be useful, they represent the HIV epidemic five to ten years prior to the collection of case data. Gender ratios may change if the definitions of AIDS-defining illnesses are revised. Information may be biased if health service access and utilization vary.

In collecting data about gender relations, care must be taken not to confuse "gender" with "women". Gender is about the relations between men and women as socially and culturally constructed in any society. In the present context, gender has to be considered as it affects susceptibility and vulnerability.

- Social differentiation: All societies are composed of different groups and subgroups. Data must be collected about these groups according to their relative susceptibility and vulnerability and the factors increasing or decreasing exposure to these risks. Generally speaking, social scientists collect data in relation to certain broad categories of social and cultural differentiation that can be seen to underlie self-imposed and other identities in societies. The main categories of differentiation to explore should be established from background information about a country that is derived from published and unpublished sources and from interviews and focus groups. They will certainly include all or some of the following:
  - occupational, income, and wealth classes;
  - status groups such as castes: groups identified as "noble" as opposed to "common";
  - gender (see Gender relations above);
  - ethnic groups, including self-defined and other cultural and/or religious and/or "racial" groups that form the basis of identity.

All of these characteristics must be examined in relation to the ways in which they affect social and economic processes so as to influence susceptibility and vulnerability. These processes include:

- livelihood strategies of specific groups;
- groups' abilities to transform their endowments into entitlements;
- resultant characteristics of sexual networking.<sup>5</sup>
- *Civil society organizations*: Information about the types, activities, and characteristics of civil society organizations must be collected to permit some

- estimate of the possible response capacity of a society to the demands of the epidemic. Such data may include information about religious charities, political organizations, citizens' organizations, and local organizations and clubs
- Structure and capability of government: In this category, data are required about the way state administration operates, and about regional and local government organization insofar as these bodies affect the ability of a society or subunits of a society to respond to the impact of the epidemic.

The consultants must consider the possible implications of the epidemic, in terms of personnel and other issues, for the activities of both of the above categories.

Special social groups: It may be important to collect data about special social groups. Each study must determine for its own purposes which groups constitute special social groups. For example, a special social group may be a group that is very obviously a "high-risk" group according to existing epidemiological studies – long-distance lorry drivers are a case in point. Other special social groups may not be so obvious to authorities or to the researcher because they are socially invisible or stigmatized. For example, male prison populations and the elderly may be important, the former for reasons of special susceptibility, the latter for reasons of special vulnerability.

#### Sectoral Data

In order to establish which sectors are likely to be affected by the epidemic, an analysis of sectoral susceptibility and vulnerability is necessary. The method for carrying this out is described for governments in "Toolkits for developing country governments" and for donor agencies in "Considering HIV/AIDS in development assistance: a toolkit". The former will shortly be available through a number of websites including that of USAID; however, the best route will be via the Health Economics and HIV/AIDS Research Division of the University of Natal, at <a href="https://www.und.ac.za">www.und.ac.za</a>. The donor agency toolkit is at <a href="https://www.worldbank.org/aids-econ/toolkit/index.htm">http://www.worldbank.org/aids-econ/toolkit/index.htm</a>.

Essentially, the data collected for economic analysis should be obtained for the sector and applied to address three key issues:

- 1. Will there be enough labour of the right type and at the right time?
- 2. What effect will increased morbidity and mortality have on the cost of employee benefits?
- 3. How is the labour used?

Skilled and unskilled labour should be assessed separately. The checklist in Table 2 provides a clear indication of the data that are needed.

<sup>&</sup>lt;sup>5</sup> This means that analysis should be made of the ways in which gender inequalities and beliefs about sex and sexuality in any particular society result in particular rates of partner change and numbers of partners over the sexual careers of members of subgroups of the population. For more information about sexual networking, see Tim Dyson (ed.), Sexual behaviour and networking: anthropological and socio-cultural studies on the transmission of HIV (Liège, Belgium, International Union for the Scientific Study of Population, circa 1996).

#### **Epidemiological Analysis**

Any impact analysis has to begin with a clear understanding of the size, location, and projected course of the epidemic. This is achieved using the surveillance data. One of the common features of the socioeconomic impact studies done to date is that all contain a section describing the epidemic. It reviews the available data and sets out AIDS case by year, age, gender, and, if possible, transmission category. HIV data are presented for specific groups, and where annual surveys have been carried out among women who attend ANCs, it will be possible to show the trends nationally and/or in specific sites. Data may be available by age and for some socioeconomic characteristics such as urban/rural residence, number of children, and so on. The issue of the types of data to be used is discussed in "Surveillance Data" above.

On the basis of the information obtained from these sources, the consultants should be able to:

- form a broad idea of the geographical and social location of the epidemic;
- establish the stage of the epidemic;
- make a judgement as to the shape and gradient of the epidemic and perhaps also of sub-epidemics;
- develop scenarios as to the likely course of the epidemic. Epimodel is a tool that can be used.<sup>6</sup>

The information obtained from this stage of the process should be constantly reviewed. It forms one of the two legs upon which the assessment will stand. It will also allow the presentation of a graphic picture of the epidemic in the area for which the assessment is being done.

#### Assessing the Demographic Effects

The reason to take account of demography is that AIDS causes prime-age adults to fall ill and die. In essence, concern focuses on a society's dependency ratio and what that means for social support systems and economic productivity, as well as the effect on demand for services.

#### Projecting the Epidemic

In order to assess the likely impact of HIV/AIDS, it is necessary to have an idea of the future course of the epidemic and, hence, how many people will fall ill and die. Mathematical models (which are translated into computer programmes) may be used to create projections of the future course of the epidemic and the consequent impacts, and, more specifically, to estimate the magnitude of these impacts. There are several different types of models in use and several software packages available for projecting the HIV/AIDS epidemic. These range from the very simplistic to the highly complex.

<sup>&</sup>lt;sup>6</sup> Epimodel is not currently recommended for use by UNAIDS as it does not make use of the wealth of new data that are becoming available. UNAIDS is preparing a new version of Epimodel, which will be made available through the UNAIDS website.

#### **Projections and Models**

In order to produce figures as to the future course of the disease, projections are prepared. These make use of computer models. However, the terms *projecting* and *modelling* are often used interchangeably.

HIV/AIDS projection models may be used for several different purposes:

- projecting HIV prevalence and numbers;
- projecting future numbers of AIDS cases, AIDS-related deaths, and orphans by year;
- examining the demographic impact of AIDS and addressing questions regarding the impact of AIDS on population growth rates, the population age structure, numbers of orphans,<sup>7</sup> and life expectancy;
- simulating different intervention strategies and comparing their strengths and weaknesses;
- assessing the impact of the AIDS epidemic for example, in terms of increased health expenditure and interactions with other diseases such as tuberculosis;<sup>8</sup>
- creating different scenarios to illustrate the effect of different assumptions on the projected outcome.

In order to use models to create projections of the future course of the HIV/AIDS epidemic and its likely impact, it is necessary to have reliable information about the current situation. Although all models depend on data, the amount and type of input data required will depend on the model being used and the questions that need to be answered. Projection models (such as the Spectrum package of models discussed in more detail in Annex A<sup>9</sup>) require demographic data as well as HIV and AIDS data. Typical information would include: current population size (broken down by age and sex); current fertility, mortality, and migration rates and assumptions about future trends; estimates of current HIV prevalence and assumptions about future trends; and assumptions about variables such as the HIV incubation period, perinatal transmission rates, age and sex distribution of new transmissions, and the start year of the epidemic. It is wise to draw on the expertise of a multidisciplinary team because of the varied nature of the knowledge required to produce sensible projections and interpretations.

It is important to keep in mind that models are simply tools that may be used to guide decision-making. Models are by definition a *representation* of an *aspect* of reality, and they cannot possibly replicate the complexity that the real situation presents. Furthermore, the degree to which the outputs of models are applicable to the real world depends upon the nature of the model itself and the reliability and validity of the data that are used. When using models it is important to bear in mind what the model was designed for and what its limitations are.

 $<sup>^{7}</sup>$  On their websites UNAIDS and UNICEF have models on the calculation and estimation of the number of orphans.

<sup>&</sup>lt;sup>8</sup> These types of projection may be done with Spectrum software available from the Futures Group.

<sup>&</sup>lt;sup>9</sup> The Futures Group family of models is available from http://www.tfgi.com/software/spec.htm.

#### **Outputs**

The model can produce the following projections:

- HIV prevalence for female, male, adult, and total population, both as percentages and numbers;
- HIV-positive births;
- adult and child illnesses;
- adult and child deaths;
- the effect on the size and structure of the population;
- numbers of orphans;
- the impact of successful interventions.

The ideal would be to have one or more scenarios. One benefit of working with scenarios is that it avoids the impression of spurious accuracy. Typically, three scenarios can be produced: a low one with optimistic assumptions, which include an assumption of behavioural change; a high scenario with pessimistic assumptions, which include an assumption of no response to the epidemic; and a middle (or most likely) projection.

#### **Economic Impact Analysis**

#### Macroeconomic Impact

The macroeconomic impact of AIDS is difficult to assess. Most studies have found that estimates of the macroeconomic impacts are sensitive to assumptions about how AIDS affects savings and investment rates and whether AIDS affects the best-educated employees more than others. Few studies have been able to incorporate the impacts at the household and firm level into macroeconomic projections. Some studies have found that the impacts may be small, especially if there is a plentiful supply of labour and worker benefits are small. Other studies have found significant macroeconomic impacts. The magnitude of the impact depends partly on the structure of the economy. Economies based on extractive industries or export agriculture are likely to be most severely affected. Unless highly qualified economists are to spend time trying to assess the impact of AIDS, it is likely that the output of the Spectrum model will be sufficient for the study.<sup>10</sup>

<sup>&</sup>lt;sup>10</sup> The model most commonly used for detailed macroeconomic modelling is MacroAIDS, developed by John Cuddington at Georgetown University, Washington, D.C.

#### Sectoral-Level Impact<sup>11</sup>

The aim of sectoral-level analysis is:

- 1. identification of the most important sectors and subsectors for the economic life of the country as indicated by official statistics;
- 2. identification of any major plants, areas, or institutions contributing more than X per cent to the overall sector;
- 3. within these subunits, identification of key plants and their key processes (e.g., maintenance of a crusher in a sugar mill supplying the country's sugar needs, with no alternative source other than imports consideration of the relative susceptibility of the maintenance engineers and thus the vulnerability of the process, the plant, and the sector; finally examination of alternatives for replacing engineers or other staff whose premature illness or death might place particular stress on the sector);
- 4. establishment of the impact of the epidemic on baseline efficiency in the case of the public sector and baseline profitability for the private sector.

One method of doing a sectoral-level analysis is by asking the questions set out in Table 2.

Section A of Table 2 shows the kinds of question which have to be asked to ascertain the impact of excess death and illness on a sector.

Section B sets out possible general demographic and economic trends, and suggests some questions for assessing their importance in relation to the sector being considered. These questions are necessary as AIDS has the potential to affect the size and structure of a population and how households and governments earn and spend money.

26

Guidelines for examining the impact of HIV/AIDS on sectors of the economy are available as AIDS Briefs from http://www.info.usaid.gov/regions/afr/hhraa/aids briefs/intro.htm.

#### Table 2. Checklist for Sector Susceptibility and Vulnerability

#### A1 - Labour Availability

- (i) Is there sufficient labour available?
- (ii) Are new recruits available? Labour may be available initially, but can it be replaced?
- (iii) Are there seasonal constraints? Are there peaks in the supply of and demand for labour?
- (iv) Does the work require experience? Some jobs do not require training but are learnt through experience; this type of employee will be difficult to replace.
- (v) Is there sick-leave provision? If so, how much? Although sick leave is a benefit, it will have an impact on labour availability. It is not unreasonable to expect employees to take all the sick leave they are entitled to. This can affect labour availability, especially if benefits are generous.
- (vi) Is there any compassionate leave? Increased mortality will increase demand for compassionate leave

#### A2 – Employee Benefits

- Are medical services or medical aid provided? The effect of AIDS will be to increase the demand for medical care, whether supplied or paid for by the sector, company, or project.
- (ii) Are death benefits provided? If employees or their dependants receive death benefits such as ex gratia payments or coffins, increased demand will increase costs.
- (iii) Is insurance provided? AIDS means claims increase and either premiums rise or benefits
- (iv) Is a pension provided for dependants? Pensions for contributors cease at their death, but some schemes provide for spouses and dependants. These will continue to pay out. In the event of AIDS deaths, it is likely that children will be left and the contributor will not have paid enough in contributions to cover the benefits that will be paid out.
- (v) Are there other benefits (e.g., housing, transportation) that might be affected by increased morbidity and mortality?

#### A3 – Use of Labour

- (i) Does work demand travel? Workers who travel as part of their work (e.g., military, transport sector) are more likely to engage in risky behaviour.
- (ii) Are migrant workers employed? Migrants are more likely to undertake risky behaviour, because they are separated from their families.
- (iii) Are male or female employees predominant? In some settings where the employees are mainly male or female, there may be more risky behaviour.

#### B1 - Demographic Trends

- (i) Is the population growth rate significant? AIDS has the potential to reduce the rate of population growth. If the sector assumes a certain level of population growth (e.g., planning for new schools is based on a calculation of the size of the school-age population), then the impact of AIDS must be considered.
- (ii) Is the population structure important? AIDS will have a marked impact on the structure of a population as certain cohorts will be more seriously affected than others.
- (iii) Is household size and composition important? As people in their twenties and thirties die, they will leave children who need care. This may change both the size of households and their composition.

#### B2 - Income and Expenditure

- (i) Will changes in government budgets affect the sector being studied? AIDS will increase demands for expenditure on health and social services and decrease resources available for other sectors.
- (ii) Will changes in taxation affect the sector being studied? It is possible that tax rates may have to rise to pay for increased health and welfare expenditures at a time when total tax revenues are dropping due to increased morbidity and mortality.
- (iii) Are changes in household income and expenditure significant? As households lose incomeearners and/or take in orphans, both income and expenditure patterns may change.

In addition to these general questions, questions specific to individual sectors should be raised. Issues for each sector should be examined, especially their specific inputs and outputs.

This kind of analysis (general sectoral-level) should be extended to all major sectors of an economy and in particularly vulnerable sectors and subsectors. The analysis should/could be extended to specific plants, enterprises, installations, or organizations. These units can then be subjected to an institutional audit.

#### The Health Sector

A socioeconomic impact study may be expected to look at various sectors or government services, depending on the terms of reference. The sectoral analysis discussed above provides a framework for doing this, but the one sector that should always be considered is health. The health sector sees the first impact of AIDS. This is hardly surprising, as people who are experiencing periods of ill-health will seek medical care. In assessing the impact of AIDS, the emphasis is on the public-sector health care system. For the private sector, in the short term, increased illness will present an opportunity rather than a threat. However, it should be noted that in some settings the private sector provides a significant percentage of treatment, usually through employment-linked health insurance. As the epidemic develops and individuals use up their resources or become ineligible for medical insurance because they lose their employment, they have the choice of going without care or seeking it in the public sector. Although the private sector may offer a way of mobilizing resources, it is driven by profit motives and so may not be the most efficient or cost-effective way of providing the type of services wanted.

The impact on the public health care sector will be one area of concern for this type of (socioeconomic impact) study. Essentially, five types of questions need to be asked. (It is important to note that volume data may give a more accurate picture than the cost data.)

- What effect will AIDS cases have on the demand for public health care?
- What are the potential costs?
- How are the government and Health Ministry likely to react?
- What will the effect of AIDS cases be on the supply of health professionals?
- How is the service organized and how efficient is it? What is its planning and management capacity in relation to human resources and other issues that make it more or less able to manage impact?

Answering these questions could be a study in itself. However, the following methodology can be followed in order to carry out a quick assessment.

- 1. Estimate the number of AIDS cases (using a projection model).
- 2. Estimate the increase in the demand for public-sector health care. This should

be done by looking at what percentage of people use public health care facilities and expecting the same percentage of AIDS cases to use these facilities. The underlying assumptions are: (a) all AIDS cases will be new demand on the health system (given the age profile, this is realistic); (b) AIDS cases seen by the private or traditional sector will not seek public-sector health care (given the tendency for people to use their resources, this may tend to underestimate longer-term demand).

- 3. Estimate the cost per AIDS case by: (a) using the general rule that each case costs 2.7 times the per capita GNP; (b) looking at the cost per case in similar countries where studies have been done; (c) estimating the percentage of patients needing treatment for HIV/AIDS in the public health sector in order to get a figure of resource utilization of the existing budget; and (d) developing a specific cost per case estimate for the country. There was an attempt to follow these procedures in the preparation of the World Bank book *Confronting AIDS*, and the work can be found in the edition of selected background papers of that book.<sup>12</sup>
- 4. Show the cost of care as a percentage of the Ministry of Health budget currently and into the future, assuming the health allocation retains a constant share of the national budget.
- 5. Show the likely effect of increased mortality on health care professionals, assuming they have the same levels of HIV infection as the 20–40 age cohort in the population.

One question that may be implicit is: What level of treatment can be afforded? In Latin America a great deal of health care is provided by the quasi-governmental Social Security Institutes. These are being forced, through legal challenges, to provide expensive antiretroviral therapy, which has the potential to use considerable resources.

Similar assessments can be done for the other service-producing sectors, such as welfare and education.

#### Institutional Audit

An institutional audit attempts to make a judgement as to whether an organization is vulnerable to the impact of HIV and AIDS. It approaches this problem by means of "bottom-line analysis". This means that it asks a hard-headed question — Will the organization be able to operate in an environment where its personnel are becoming infected with HIV and ill with AIDS, and are ultimately dying? In the case of a private-sector firm, the issue will be the loss of profitability and in extreme cases the survival of the firm. For government ministries, parastatals, and nongovernmental organizations, the issues centre around the levels of service provided and demanded and the effect on these. Apart from the requirements of the local legal system and reasonable morality, no account is taken in such an analysis of the emotional suffering of personnel or other issues. The bottom line is always whether the organization can continue to exist in the foreseeable future. The benefit of an institutional audit is that it can be done for and with any organization or institution.

See M. Ainsworth, M. Over, L. Fransen (eds.), Confronting AIDS – evidence from the developing world: selected background papers (Brussels, European Commission, 1998), Part 3, pp. 239–322.

#### Techniques for Assessing Institutional Vulnerability

This section provides suggestions as to how an institutional audit might be undertaken. The main steps are presented (there is inevitably overlap with sectoral analysis), and are followed by some general comments.

- Step 1. Personnel profiling: What kinds of people are employed?
- Susceptible groups: Are there particular groups among employees who may be particularly exposed to infection? Why are they exposed? Can/should the organization do anything to reduce this exposure? Will undertaking such programmes benefit the organization? Should all employees be included or only those who are most difficult to replace?
- Skill levels: What skill levels are there in the organization? How many people are employed at each level? Given the known and predicted rates of seroprevalence, and assuming that the organizational population reflects the wider population, how many people might be expected to become ill or die in each year over the next X years in each category of employment?
- Ease of training and replacement: How easy will it be to train or recruit personnel at each skill level? (Consider costs and time for training and also the state of the national and regional labour market in relation to these skill levels.)
- Step 2. Critical post analysis: Are there key personnel whom it will be particularly difficult to replace? Are there key personnel on whom a production or administrative process depends (e.g., "institutional memory", or the person who knows how to use the computer). Such people may be difficult to replace.
- Step 3. Organizational characteristics: These questions deal with the size and "depth" of the organization. How easy will it be to replace or retrain within the organization? Are there sufficient people to allow for internal training? Should the organization introduce "shadowing"? How big is the organization? Does it have sufficient internal resources to be able to undertake replacement and/or training of personnel? Is it big enough to move people around to take over other people's jobs? What is the lead time for training or recruiting a replacement for different skill levels?
- Step 4. Liabilities: The potential or actual liability of the specific organization will be determined by the following factors:
- Level and type of employee benefits: These are related to contracts of employment. What kind of contracts do staff have, including medical benefits and pensions?
- Level of labour value added: For a production or commercial organization, this measures the part of gross profit attributable to the work done by labour. Variables are: quantity and quality of labour (seen in levels of pay); labour as a proportion of all inputs to production (e.g., in a software design enterprise, the labour value added will be large).
- Step 5. Productivity: This refers to the reduction in the quality and quantity of labour supplied by employees who are sick or who may be caring for sick dependants. Absenteeism may result in a slow and hardly detectable decline in output in any organization. How is this going to be detected, and coped with?

- Labour/capital substitution: Can capital be used to replace people who are sick or who have died, thus avoiding that risk in the future? Could larger numbers of unskilled workers replace the lost skilled workers?
- Outsourcing and multi-skilling: Can non-core functions (e.g., security and cleaning) be outsourced? This is a possible solution for the enterprise, but it must be noted that while such tactics will shift the problem from the company, it will not solve the problem at a sectoral level. Can staff be trained to have multiple skills, thus enabling them to do their own and others' jobs should the situation demand it?
- Step 6. Organizational context: What is the law?<sup>13</sup> What must an organization do for its workers in the way of invalidity benefit, keeping them at work when they are HIV-positive but not ill or when they have AIDS but are not too sick to work?
- *Employee organizations*: What power and attitudes do trade unions and political parties have in the area of HIV/AIDS and the rights and interests of employees?

#### Some Basic Principles

Early response to the epidemic is important for organizations, as for everyone else. Responses may occur at any of the following five stages:

- the appearance of HIV in the wider community;
- the sporadic occurrence of illness and death in the organization;
- the first significant interruption of or disruptions to work caused by continuing employee illness, absenteeism, or death;
- the recruitment and training of new employees in response to greatly increased employee mortality or morbidity;
- the recognition that the entire way of working in the organization must be redesigned to cope with the epidemic.

The following points should be noted:

- The total cost to the organization will be significantly reduced if the decision to respond is pre-emptive and early rather than responsive and late.
- Effective management information and monitoring systems aimed at management are important in developing pre-emptive strategies and subsequent responsive strategies as the epidemic increases its impact on the organization.
- In sizeable organizations with large numbers of people at risk, succession-planning strategies should be considered and costed in outline. This should be done on the basis of a personnel profile exercise so as to explore substitution by multiple recruitment, multi-skilling, and skill-pooling by key people.
- Assessment of the organization's financial risk exposure should be made on the basis
  of existing benefits packages, types of contracts, and actuarial calculations of risk.
- Where appropriate and cost-effective, the organization could implement workforce education and extend education to workers' households so as to reduce workforce susceptibility.

 $<sup>^{13}</sup>$  This might include international norms, national legislation and regulations, and agreements with employees right down to the shop-floor level.

The steps to be undertaken for a generic institutional audit are shown in Table 3.14

Table 3: Steps and Processes of an Institutional Audit

	<del>-</del>			
Activity	Justification	Outcome	Resources	Challenges and assumptions
1. Internal (and if necessary external) performance/ impact appraisal of the organization	Increase productivity Establish base profitability Establish base sustainability	Identify the necessity and nature of institutional audit, particularly whether, and how many of, the next steps are necessary, whether, and how many of, the steps set out in the text are necessary	Annual financial statements, sectoral legislation, mission statements, strategic plan, and previous budget	Systematic organizational management/ monitoring tools are used and reports are available
2. Establish the current profile of the organization (e.g., use SWOT analysis – identify strengths, weaknesses, opportunities, and threats)	Identify new opportunities and possible threats, minimize impact of weaknesses, maximize potential of strengths	Potential susceptibility/ vulnerability are agreed upon and prioritized in the order of their potential impact on institutional productivity and/or sustainability	Consolidate Management Information System (MIS) <sup>15</sup> reports and performance appraisals Independent facilitators and arbiters	MIS and/or performance and/or appraisal systems exist and can be used
3. Detailed diagnostic assessment (described in detail in the text)	Define the cost the impact of vulnerabilities that have been identified	Establish baseline for measuring future productivity/ sustainability and/ or organizational growth potential	Outcomes of steps 1 and 2 above	The organization has come this far in its analysis and still believes it has a role, a potential market, an effective workforce
4. Environmental Survey	Quantify the potential market(s), agree on strategies for and risks involved in continuing in same market, expanding into another market or ceasing to operate in this market	strategic objectives, targets, and performance standards	Paper/time  Consultants and other specialists	That the previous steps have been completed

<sup>&</sup>lt;sup>14</sup>This table is based on ideas developed by Dennis Bailey at a Social and Economic Impact Policy Research Workshop in Durban, South Africa.

<sup>&</sup>lt;sup>15</sup> Management Information System (MIS) is a system of data collection and organization designed to provide management with information that will answer key strategic questions (e.g., How many people and at what levels are taking sick leave, early retirement, compassionate leave? Which grades of employee are taking what periods of sick leave or early retirement, and what are the causes of these absences and retirements? At current rates of sickness, early retirement, and death in service, how many years of work might be expected from each year of training or unit cost of training? At which points in the organizational process is it clear that unexpected absence, early retirement, or death in service will affect the smooth operation of the enterprise?).

#### Social Impact Analysis

#### Social Structural Impact

The idea that societies have "structure" is useful for considerations of impact. Societies have structures that exist in fluid ways and that may change their form, meaning, or relationships to each other. This is a complex idea, but it can be illustrated by the following three examples from diverse societies. The key questions to be asked in each case are: Which social groups are in short supply and are of strategic importance to the operation of society in terms of the supply of skills, talents, and capabilities? Are there any social groups that are currently emerging and therefore may be in short supply?

- In many western societies, income and occupation classes are important social markers of prestige and status as well as of wealth. Over the past 100 years, the hierarchy of wealth and income has altered in many respects. Nevertheless, a hierarchy remains, although its social meanings and precise make-up and ordering have changed. Examples of change in recent decades might be that "professional" groups have become less socially valued as they have encountered more competitive and less ideologically protected environments. This may mean that their control over allocation of resources is now less pronounced than once was the case. In contrast, with the development of a more competitive information-based economy, technical specialists in these fields are now in shorter supply and are more important to the effective operation of society than are the old professional groups.
- Countries of the former Soviet Union were previously characterized by centralized government and control through the party and its personnel. These people were crucial to processes of organization and production of social support systems. Recent political and economic changes have changed much of this. The formerly powerful party and state personnel have either lost their positions or have transferred their former influence into the private sector. In response to change, there is now a growing class of mainly young, highly mobile people who exercise their entrepreneurial skills in the business, NGO, and remaining state sector. They may also be active in a variety of illegal and semi-legal activities. This new social segment may be seen as possessing skills and capabilities that are in short supply.
- In Uganda, as in many other parts of the world, individuals have taken much of their identity and their expectations of support from their immediate family and, ultimately, from their much more extended kin group, sometimes called a lineage. In circumstances of adversity, these have been expected to offer support and welfare. In the early days of the HIV/AIDS epidemic, it was expected that these social units would cope with the burden of orphaning. This has turned out to be only partially the case, as the numbers of orphans has exceeded their ability to cope. They have to some extent now been replaced or supplemented by various forms of fostering, institutional care, and NGO support. In such cases, it may be that the lineage elders are of less direct importance than the supply of trained NGO workers a group that may itself, because of age and education, be particularly susceptible to infection, making these "new" organizations vulnerable to the impact of the epidemic.

Inevitably it is difficult to assess potential impact within these social groups, because opinions and circumstances as to the relative importance of different social groups will vary dramatically between and within societies. Such issues may be the subject of current political debate.

Another way to approach the issue of social structural impact is through the framework of human resource endowment. Estimates need to be made of the numbers of available people with particular skills in a given society and how susceptible these people are to infection.

In principle, making these estimates appears a straightforward task. How many doctors are there, and in what specialties? Where are they located, and what is their age distribution? Such data might be established for a variety of key professional groups. Judgements are inevitable as to the relative importance of different occupational groups. In particular, it should not be forgotten that there are many occupations that may be judged of low status but that are of great social, cultural, and economic importance. Examples might include locally trained mechanics, most unpaid women's occupations associated with the farm and the home, and ritual specialists. Clearly, these are very difficult judgements to make, but some such estimate is necessary if impact is to be correctly assessed.

#### Social Scale and Location

So far this manual has been concerned with the impact on society as a whole. However, it is most difficult to discern impact at this scale. The process of impact identification must be taken down from the macro to the meso and micro levels. Here the ideas of susceptibility and vulnerability are again the guides. Where in society and the economy are groups of people and organizations and social institutions most likely to be susceptible to infection, and which of these are most likely to be vulnerable to the impact of loss?

Some examples will assist in understanding the problem. At the macro level, it may be assumed that excess morbidity and mortality will impact upon "households". The question is, which households? To answer, it is necessary to start from what is known of the spatial distribution of the epidemic as indicated by sero-surveys, sentinel surveillance, reported cases, and any other available sources. This gives us a broad indication of "where". It must be remembered, however, that this answer is to be treated as provisional. It may be an artefact of the reporting system as much as an indication of what is happening. When a location has been identified, the consultants will want to consider its households in terms of their relative susceptibility and vulnerability. An example can be taken from a study in Ukraine. Information about seroprevalence and reported AIDS cases and, in particular, about injecting drug use indicated that households in an area of declining industry were very susceptible. This gave the location. Within this location, the most susceptible households were likely to be among those where there was no wage-earner. The most vulnerable were those households where there was no income-earner (for example, the household was made up of the elderly) or where the household had a large number of dependants.

A similar exercise has been undertaken in Uganda, where sero-data were used in conjunction with farming system data to identify areas where excess mortality or morbidity would have the most pronounced impacts on production and the household's welfare. <sup>16</sup> Within the identified spatial unit, the most vulnerable households could then be identified in relation to dependency ratio and asset endowments.

<sup>&</sup>lt;sup>16</sup>See T. Barnett and P. Blaikie, AIDS in Africa: its present and future impact (London, John Wiley, 1992; and New York, Guilford Press, 1994).

### **Development Impact Analysis**

While there are debates about exactly what constitutes development, there are certain "gold standards". Development should represent an improvement over the status quo. Most countries work from development plans, which set out national goals and targets, and how money will be spent to reach these targets. Global development goals tend to be set by donor agencies (see Annex C for OECD development goals), and UNDP has developed indicators to measure levels of development.

### Measuring Development

UNDP states that "the purpose of development is to create an enabling environment for people to enjoy long, healthy and creative lives". <sup>17</sup> In order to measure this, it uses the Human Development Index (HDI), which combines three indicators of the most basic human capabilities — leading a long life, being knowledgeable, and enjoying a decent standard of living — to give the index of human development by country or region. Variations of these basic indicators have been developed to produce a Gender Development Index (GDI) and Human Poverty Index (HPI). Increasingly planners and policy-makers look at UNDP's methods of measuring development. It is therefore important that the report should consider the effect of AIDS on these indicators. The best way to accomplish this is to take the methodologies of calculating the HDI, HPI, and other indicators and apply the modelled impact on life expectancy to them.

The changes in life expectancy and ranking in the global human development table are shown for selected African countries in Table 4. The 1996 *Human Development Report* used 1993 life-expectancy figures, and AIDS was not considered. Since 1997, AIDS has been taken into account, but not consistently. The table shows that this loss of life expectancy has a dramatic effect on the standing of countries in the world ranking.

Table 4. Life Expectancy and Place in the HDI<sup>18</sup>

	1996		19	97	19	98	19	99
Country	Life expect.	Rank	Life expect.	Rank	Life expect.	Rank	Life expect.	Rank
Botswana	65.2	71	52.3	97	51.7	97	47.4	122
South Africa	63.2	100	63.7	90	64.1	89	54.7	101
Swaziland	57.8	110	58.3	114	58.8	115	60.2	113
Namibia	59.1	116	55.9	118	55.8	107	52.4	115
Zimbabwe	53.4	124	49	129	48.9	130	44.1	130
Kenya	55.5	128	53.6	134	53.8	137	52	136
Zambia	48.5	136	42.6	143	42.7	146	40.1	151
Malawi	45.5	157	41.1	161	41	161	39.3	159

<sup>&</sup>lt;sup>17</sup> United Nations Development Programme, *Human development report 1999* (New York, Oxford University Press, 1999).

<sup>&</sup>lt;sup>18</sup> United Nations, *Human Development Reports* (New York, Oxford University Press, 1996, 1997, 1998, 1999). Note that the life expectancies used for calculating the Human Development Index are for 1993, 1994, 1995, and 1997 respectively.

### Presenting the Findings

A significant number of reports on the social and economic impact of AIDS have been commissioned and written over the past ten years. Most are prepared, presented, and forgotten. If an impact report is to have an effect it must include:

- material that can be used in advocacy;
- suggestions for action.

The structure of a report might follow the sections of these guidelines. It should contain:

- 1. Terms of reference: A statement of the terms of reference of the impact assessment.
- 2. Description of the society being assessed:
- the name of the country;
- a brief historical account of the country;
- a brief account of the current political, social, and economic situation;
- a brief account of the population size and structure and the main administrative and social divisions;
- a consideration of the current position of the country on the Human Development Index and the standards and levels of welfare provision;
- any particular cultural features of the society that are relevant to the later analysis.
- 3. Epidemiology:
- a description of the epidemiology of the disease as far as it is known;
- projections of the epidemic showing high, medium, and low estimates, together
  with main locations of infection both social and spatial as well as an
  assessment of the accuracy and dependability of these data in relation to the
  existing reporting systems;
- a note on any particular features of epidemiology relevant to impact assessment.
- 4. Demography:
- a description of the demography of the country, indicating any peculiar features such as unusual numbers of young or old people, gender imbalances, together with indications of with- and without-AIDS life expectancy, age-specific mortality rates;
- projections of demographic structures under assumptions of different levels of infection, indicating the effects of different levels of infection on dependency ratios, numbers of orphans and elderly dependants, numbers in the 15–45 age cohort over time.
- 5. Susceptibility and vulnerabilty:
- a general account of the particular features of the society that make its structures and processes contribute to increased or decreased levels of susceptibility;

a general account of the particular features of the society that may make it more
or less vulnerable to the impact of the epidemic.

#### 6. Economic impact:

 a detailed analysis of economic impact following the outline structure indicated in these guidelines.

#### 7. Social impact:

 a detailed analysis of social impact following the outline structure indicated in these guidelines.

#### 8. Development impact:

• an assessment of the impact of AIDS on development indicators and the implications of this.

#### 9. Summary and policy implications:

- a summary of the main findings;
- key policy implications of the impact assessment, indicating the time span within
  which policies might be necessary and the expected results, including outline
  indicators for monitoring and evaluating the effectiveness of policy and, where
  possible, some indications of the cost and feasibility of different policy options.

#### 10. Executive Summary:

• an executive summary of not more than 2,000 words, which should be placed at the front of the report.

It should be noted that this structure is most useful for a broad impact assessment. There will be variations with specific sectoral documents.

## Part 3. The Conceptual Framework

Socioeconomic impact studies can be, and usually are, commissioned by people who do not have a clear idea of what these studies can and cannot do. Clients often expect the study to tell them exactly what they should do. Thus it is important for all studies to have a conceptual framework that is clear to all parties.

A review of the terms of reference of many of the social and economic impact studies carried out to date, and of those reports available, shows that they implicitly had the dual function of identifying target groups for prevention and areas of impact for mitigation. They generally failed in both goals because the implicit objectives were not made explicit, and the identification of impact was too complex for the studies. This manual suggests that the targets should be made explicit if studies are to be of value.

In this part we examine the concepts of:

- impact in general
- epidemiological and demographic impact
- social impact
- economic impact
- timescale in connection with such studies
- susceptibility and vulnerability.

## Impact in General

The impact of AIDS flows from the increase in premature morbidity and mortality that it causes. A general working definition is that impact is:

- A shock to an existing system of livelihood at the national, regional, communal, or household level, which reduces the levels and expectations of life and welfare.
   It may mean the dissolution of the unit and involve the loss of individuals from poverty-related causes rather than as a direct result of HIV/AIDS illness or death.
- A slow but complex set of changes to a social and economic system, attributable
  to the effects of an identifiable set of causes. In this context those causes are
  increased illness and death associated with HIV/AIDS.

In the very much longer term, we should not overlook the possibility that in some cases the epidemic may have economically and socially positive impacts. However, for most individuals, households, and communities affected by the epidemic, impact will be experienced only as negative.

The extent and the precise nature of impact will depend on a wide range of factors. Among them will be:

- the number of people infected and the time between infection and death;
- the rate at which the epidemic moves from being concentrated in particular population subgroups to becoming established in the wider population;
- the rate at which the virus is transmitted and thus the shape of the epidemic curve, in particular the speed with which it spreads (its gradient) and the highest level it reaches (its peak);
- the social, cultural, and economic location of those infected in terms of key social indicators (These will vary in significance from one society to another but may include: income, occupation, gender, ethnic affiliation, religion, spatial location, and/or geography. Of particular importance will be the question of the ways people make their livings (livelihood strategies) that involve spatial and social mobility, conflict with existing legal dispensations, crossing socially and culturally approved boundaries in any particular society. In other words, it is important to consider the ways in which making a living exposes individuals and groups to the risk of infection.);
- the existing coping mechanisms in society (e.g., are safety nets, such as fostering grants, available from the public sector, and does the society respond in a charitable and altruistic manner to crises among its members?).

## Epidemiology and Demography: The Bases of Any Impact Study

An impact study cannot begin by looking at the social and economic issues alone. The foundation of any impact study must be as clear an understanding as possible of two sets of underlying information: epidemiological and demographic.

## **Epidemiological Information**

Epidemiological information is important in confronting issues of prevention and impact mitigation. Epidemiology permits identification of the key "risk groups" in the early stages of an epidemic and of "core transmitter groups". This enables cost-effective preventative interventions such as needle-exchange, increased condom use, and other programmes aimed at behavioural change. However, epidemiology also has a part to play in identifying the social, economic, cultural, and geographical location of groups likely to be most seriously affected by excess illness and death.

#### National Epidemics and Sub-epidemics

Information on national epidemics and sub-epidemics is also of importance because – depending on its quality and how fine a picture it provides – it can identify the separate epidemics that make up a "national" epidemic. The curve of the national epidemic will have a particular gradient and peak and so will each of the sub-epidemics

from which it is constituted. Figure 2 shows some of the typical sub-epidemics that might be identified in a hypothetical country. These differences in sub-epidemics, defined in social, cultural, spatial, or economic sectoral terms, should also give some indication of the areas of society and economy in which impact will be most pronounced and, thus, where mitigation policies would be most urgently required, assuming, as we must, less than perfect response to prevention messages.

Epidemiological information is also essential for developing projections of the progress of the epidemic. This will include the number of cases by age and gender as well as the number of deaths from AIDS. This information is crucial for the development of impact studies.

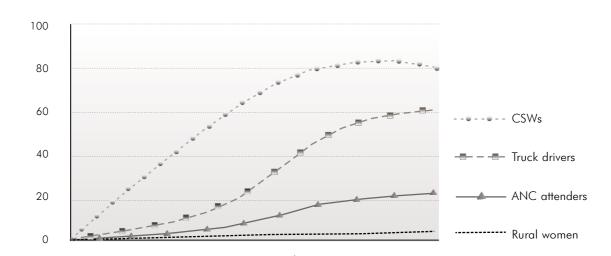


Figure 2. Projected Levels of HIV Infection in a Hypothetical Country

## Demographic Information

Demographic information is used in conjunction with epidemiological information. Studies need to take account of demography because of the effects of the epidemic on prime-age adults who fall ill and die. These people are the producers, innovators, parents, care-givers, tax-payers, employers, and employees in all societies. They also constitute the group which, under normal circumstances, is least likely to make demands on state and other health and social services. In essence the study is concerned with what this demographic trend means for social support systems and economic productivity. We cannot simply look at dependency ratios, as these may not change very much. The reason is that, although adults experience increased mortality, so do children, either because they are infected by their mothers or because the level of care is lower. Although a child born to an infected mother may have only a 30 per cent chance of being infected, she or he has close to a 100 per cent chance of being orphaned, and this will usually happen before the child's tenth birthday.

Demographic analysis must be part of socioeconomic impact studies. In most cases, an impact study will require that projections be made so that a range of population effects of increased death and illness can be considered. How many orphans will result from premature deaths, over what period and where? How many old people will be left without children to care for them, over what period and where? What numbers of adults might be expected to seek hospital treatment, over what period and where?

## Social Impact

## Social Support Systems Explained

All social support systems follow essentially the same principles. They depend on:

- contributions, which may be in cash, kind, or labour;
- distributions, which may be in cash, kind, or labour;
- systems of social relations and beliefs, which regulate the collection and allocation of resources.

These principles apply as much to small, rural community as they do to large, state-administered systems. The difference is one of scale, complexity, and intimacy. Transfers occur from some sections of the population to others and from one level to the other – for example, households and individuals may pay taxes, which are transfers to the state, and the state may redistribute these revenues. The rules and practices by which these transfers occur depend on many factors. These include:

- current political balances reflecting relative power of social groups in relation to each other;
- ethical or religious beliefs;
- cultural evaluations of age, gender, and ethnicity;
- the rules that are derived from these balances and evaluations and that then determine the ways in which endowments are translated into capabilities and ultimately into entitlements.

The end result of these processes is a range of states of well-being for different population groups and subgroups. States of well-being may be seen as falling along a continuum – from an assured belief that expected levels of health, nutrition, and security will be met from available resources over the foreseeable future to a sense that none of these is certain, that the foreseeable future is short, and that values and norms are widely questioned and uncertain. The degree of equality or inequality in the distribution of resources and valued goods and services, which forms the basis for people's assessment of their expectation, will depend on local cultural traditions, political decisions, and beliefs.

In relation to an epidemic of HIV/AIDS, the range of states of well-being is of

particular importance in the following ways:

- There are indications that poverty, wealth, and expectations of level of life can, in different circumstances and for different reasons, make individuals and groups more or less susceptible to infection.
- Excess mortality and morbidity affect the lives of those who are not ill or dying as well as those who are not even born but who will be entering a society in which resources may be more constrained than they would have been had the society not experienced excess death and illness associated with the epidemic.
- There is the possibility that excess mortality may in some circumstances result in improved well-being for those born later in the epidemic. Although this may seem callous, the possibility of positive as well as negative long-term social and economic impacts at the macro level should not be overlooked in any consideration of impact.

## Social Relations of Production and Reproduction

So far this discussion of social impact has been in terms of social support and the collection and allocation of material and other means of support. These means of support must be produced. The question of impact on production is dealt with under "Economic Impact" below, but social and economic impact cannot be so easily separated. Illness and death affect the ways that goods and services are produced, and even whether they are produced at all. Above all, they affect the social relations of production, the ways in which people come together to produce, the coordination and timing of production — decisions as to who shall do what, when, and how. Disruption of and change to these types of relations, whether at the level of the household, the farm, the factory, the ministry, or the whole state, will be symptoms of social impact.

Studies must also be concerned about what may be described as *relations of social reproduction*. This issue has been touched upon under "Social Support Systems Explained" and in the preceding paragraph. Social relations – whether of the household, the community, or the entire state – require constant effort if they are to continue in existence and do what people expect of them. For example, kinship and family relations may provide support in times of trouble, but only if there has been investment of various kinds in their continuing existence. This investment is not necessarily material: it could be investment of time or participation in rituals or events such as religious ceremonies or regular family and community gatherings. Similarly, relations of authority (for example, cooperation between citizens and the police force) in a state require constant demonstration that relations of trust exist between the groups. In reproducing relations of authority and kinship, the efforts may be partially remunerated or not remunerated at all, yet the structures of relationship will not continue to exist unless the effort is made.

It is in the reproduction of social relations where the social impact of premature and excess deaths may be most important and yet undetected using normal economic measures. It is here that different methods of impact detection may be necessary. These are likely to include various kinds of focus group and participatory methods if the impact is to be detected and become an object of policy consideration. Remember, one often has to look for evidence of social and economic impact.

Thus, social impact may be defined as any sudden shock or slow-acting and cumulative series of events that disrupts existing systems of social support. This includes not only the work of those who collect and allocate material and other forms of support, but also those whose work is in itself supportive of others or those whose work supports and reproduces the system of social support itself.

A matrix for assessing how social impact might in principle be identified and measured at various "levels" of society is presented in Table 5.

**Table 5. Social Impact** 

Level <sup>1</sup>	Definition	Indicators <sup>2</sup>
Macrosocial political and administrative unit	Any large-scale sociopolitical unit, including a country or the major administrative unit of a country	Breakdown of social order, changes in people's perceptions of personal safety, ability to plan for the future; expectation that there is a future; in some extreme cases, civil disorder
Sectors/regions	Any subsidiary sociopolitical unit down to but not including the level of the district, parish, or community	Increased numbers of orphans and orphaning events following a sigmoid curve; increased numbers of street children; increased reports of failure of and stress in "traditional" orphan-coping mechanisms; increased death rates among young state employees (e.g., teachers, doctors, administrators); failure of "traditional" mechanisms for care of the elderly; stress in and failure of community and regional provisioning systems; changes in funeral practices; fewer days of mourning; increased coffin or other burial goods production
Firms, enterprises, and NGOs	Any subsidiary unit	Increased rates of absence; increased rates of death in service; increased demands on medical insurance schemes; reports of loss of institutional memory and key workers; decline in institutional performance (profit lines and other measures of productivity — e.g., increased rates of power breakdowns in electricity supply system)

Table 5 (con't.)

Level <sup>1</sup>	Definition	Indicators <sup>2</sup>	
Community	The level of the district, parish, or community	Difficulties in finding personnel for local government processes; unavailability of people for meetings; increased frequency of elections as a result of more frequent deaths of representatives; increased numbers of deaths in service of officials of local government and community organs	
Households	Any unit of habitual residence where some consumption and/or production may be undertaken in common and where some members may recognize culturally defined relationships of kinship and/or affinity where the members are related in some way	Increased frequency of deaths of mature-age adults; unusual and sudden increase ordecrease in household size; unusual rates of household dissolution and reconstitution; decline in nutritional status of children; decline in school attendance, particularly among girls in the 8–15 year band; changes in cropping patterns to less labour-intensive crops in rural subsistence households	
Individual	Person	Reported actual and perceived inability to meet social and particularly family obligations	

<sup>&</sup>lt;sup>1</sup>These units of analysis are suggested for illustrative purposes only. In practice they will be defined by levels and titles specific to a particular country and in relation to the culturally specific questions raised by impact analysis in that context.

## **Economic Impact**

Economic impact can be defined as that which causes the diversion of resources to uses that would not have been necessary in the absence of HIV/AIDS, and decreased production due to the disease. In some circumstances, impact may be positive from the perspective of the unit of analysis as a whole when considered in strictly economic terms. This may occur when, for example, economically "unproductive" people die, leaving the resources of a unit to be divided between fewer people whose individual portion is then increased. This is a formal, technical economic perspective. However, it must also be recognized that people who are economically "unproductive" may well be of the greatest value when measured against other criteria, such as those of, child care, non-market, non-remunerated work on the farm or in the home, wisdom, affection, traditional obligation, and commitment, or even love.

<sup>&</sup>lt;sup>2</sup>Specific indicators will differ from place to place and will have to be developed on the basis of participatory methods that aim to translate anecdotal information into usable indicators.

As illustrated in Table 6, economic impact may be considered to occur at various levels.

**Table 6. Economic Impact** 

Level	Definition	Indicators			
Macroeconomic	National or provincial economy as defined by gross domestic or gross geographic production	A decline in GDP that can be attributed to reduced production due to HIV/AIDS Per capita GDP Gini-coefficient* or levels of poverty			
Sectors	Productive economic divisions (e.g., agriculture or banking; usually defined in national accounts	A change in output from the sector, attributable to HIV/AIDS Changes in demand attributable to HIV/AIDS Changes in operation attributable to HIV/AIDS			
Health sector <sup>19</sup>	Provision of curative and preventative care, making populations live longer and healthier	Increased mortality — Disability Adjusted Life Years (DALYS) <sup>20</sup> Increased morbidity — Quality Adjusted Life Years (QALYS)			
Firms, enterprises, and NGOs	A private or publicly owned unit producing goods or services for sale in a market or for distribution through the administrative organs of the state or through mechanisms of a nongovernmental organization – the "Third Sector"	Increased staff absenteeism Changes in productivity Deaths in service Increased early retirement Increased staff turn-over Changes in demand for output or services (decrease or increase)			
Households	A unit of habitual residence where some consumption and/or production may be undertaken in common	Changes in wealth (usually poverty) measured by reserves including money savings, land, animals Decreased levels of intake of food and/or expenditures on other forms of consumption Decreased uptake of services that require cash or time (e.g., schooling or health care)			
Individual	A single person	Lower productivity, or no productivity			

<sup>\*</sup> Economic measures of inequality of income

<sup>&</sup>lt;sup>19</sup> Since AIDS is a disease that causes increased illness and death, it is appropriate to look at its economic impact specifically through and on the health sector.

Disability Adjusted Life Years (DALYS) calculate the years lost to each disease to produce an indicator. This can be expressed as the number of DALYS lost to a disease, a percentage of the total health burden, or in relation to total population. Because health is a continuum and DALYS measure life years, a second measure was developed to measure morbidity. Quality Adjusted Life Years (QALYS) is an attempt to measure both the quantity and quality of life lost to specific diseases.

### The Macroeconomy

In the early 1990s there were a number of studies that looked at the impact of AIDS on macreconomic trends. The hypothesis was simple: AIDS would affect the macroeconomy by reducing the number and level of productive people in a nation, and by diverting resources from investment to care.

Early models found that the magnitude of impact would depend on the number and skills of the people affected and the degree to which resources were in fact diverted. Over time it has become apparent that, while it is possible to model the impact of HIV and AIDS on the national economy, it is extremely difficult to identify and measure macroeconomic impacts. This problem is made worse because economies, especially in developing countries, are constantly being subjected to shocks and pressures. There is, however, a likelihood that in some countries more sophisticated macro models may pick up the complex impact of AIDS on macro indicators.

#### Sectoral Level

The impact at the sectoral level will be more pronounced and easier to measure than that of the macroeconomy. *Sector* covers conventionally defined economic sectors such as agriculture or mining or government budget lines such as health, welfare, or defence. It may be appropriate to look at subsectors such as forestry or peasant agriculture or, in the case of government, primary health care or hospitals. The amount of sectoral detail a study can go into will depend on the time and the budget. The one sector that frequently receives attention is the public health sector. This is done with good reason: the health sector will be the first non-micro level at which the effects of the disease are seen as the number of sick people needing care increases.

#### The Firm or Institution

There are only a small number of attempts to assess the impact of AIDS on the private sector that have also been made public. It is likely that many more firms have carried out such assessments internally but have not made them public. The evidence from those studies that are in the public domain is that such impact may be limited but significant in the five- to ten-year period projections and that degree of impact will depend entirely on the type of activity, the number of workers infected, the benefits offered, and the response of the firm. In the longer term, the impact on the business environment, including the demand for goods and services and the local or regional labour market, may become important. Assessing this does not require a socioeconomic impact study but rather an institutional audit, as described in Part 2. These audits can also be seen as components in overall social and economic impact assessments and can be applied to the full range of enterprises including private-sector firms, NGOs, and government ministries and parastatals.

### Household and Community-Level Impact

A study of the impact at these levels is difficult to undertake for the following reasons:

- Households are not at all homogeneous between cultures, or even within them.
- Households change their size and constitution over time, in particular through processes of natural growth, decay, and dissolution.
- It is difficult to gain information about the internal distributional dynamics of households and thus to discern the gendered impact at this level.
- Households may split, join, or coalesce, and the impact of excess death and illness may be hard to track over a number of years as these processes occur and are combined with geographical mobility.

A study at the household level may be useful, but it is also difficult to carry out: to track AIDS-affected households a large sample will be needed over a relatively long period of time. Nonetheless, it is at this level that the impact will be felt first and worst. An important problem that should be borne in mind when considering such studies is that the earliest and most seriously affected households will disappear first – probably before the survey has been commissioned, let alone executed. This reality means that any survey of this type should be carefully designed to pick up traces of survivors in successor households or to pick up memories of households that have disappeared from communities or kinship networks.

A study of the impact of HIV and AIDS at the household and community level is a study in its own right, and very few have been undertaken (they are described in the background paper). That is not to say that this impact is not important; indeed, in the long run it is probably one of the most important impacts because of its effect on social capital and socially reproductive labour, which are the foundations of households, communities, and nations. If we are fully to appreciate the nature of impact, we must recognize and make some efforts to estimate the ways in which loss of social capital and socially reproductive labour will affect the society and economy.

## Timescale

Timescale is crucial because it has implications for data collection and projections. Many terms of reference ask for a "socioeconomic study" without giving a timescale as to how far ahead the study should look. Although the people commissioning the work will want an assessment of current and future impact, it may not be clear as to what exactly they mean by future, and how far ahead they want to go. What they usually want the study to do is to:

- assess the current impact of AIDS;
- project the future scale of illness and death, (they should be clear as to how far the projection should extend);
- predict the spatial and social location of these illnesses and deaths;
- make judgements as to what effects this illness and death will have.

The timescale over which an impact study is undertaken is a key variable. Two important points should be noted:

- As with all projection exercises, the further the projection is pushed into the future, the less certain the outcomes. To put it another way, the further into the future the projection is made, the wider the margin for error and the larger the range of possible outcomes.
- The final state(s) of the projection will be determined by the initial data. It is therefore of the greatest importance to ensure that data quality is the best possible.

In addition to these technical points, consideration must also be given to the following:

- Politicians' attention may be limited to the next five years or, at most, ten years.
  It is therefore difficult to persuade them of the need for policy responses beyond
  these time horizons even if the impact study indicates that the problems lie
  beyond those time limits.
- All administrations operate on a periodic cycle, whether this is annual, two-year, five-year, or other, and whether it is a rolling or sequential cycle. If an impact study is to be effective, its conclusions and policy outcomes must be developed in such a way that they can be fitted into the appropriate local administrative cycle.

The implication of the above is that both those carrying out the study and those commissioning it should ensure that the timescale is established and realistic. Furthermore, the implicit target of such studies is to identify, for prevention, areas where HIV infections are and might be, and, for mitigation, where cases will occur and the consequences of these infections. In order to identify such information, the concepts of susceptibility and vulnerability are used.<sup>21</sup>

48

<sup>&</sup>lt;sup>21</sup> These concepts and the ideas that lie behind them are discussed in more detail in: Tony Barnett and Alan Whiteside, HIV/AIDS and development: case studies and a conceptual framework, *European journal of development research*, 1999, 11, No. 2.

### Susceptibility and Vulnerability

Susceptibility has been defined above in Part 1. Here, it is important to note that it may be applied at the level of socioeconomic entities — an organization, service, or manufacturing enterprise, for example. Susceptibility describes the degree to which the social, economic, cultural, and environmental conditions increases the rate at which disease spreads and thus the ultimate gradient and peak of the epidemic curve.

The above factors may be considered in part to describe the "riskiness" of the environment. They be may be infrastructural (the development of a road), environmental (a drought resulting in unusual population movements), cultural (a particular sexual practice or belief, or a change in these), economic (increased unequal distribution of income), or social (the operation of labour and associated housing markets in urban areas). As a result of these factors, social units and groups may be more or less susceptible to infection.

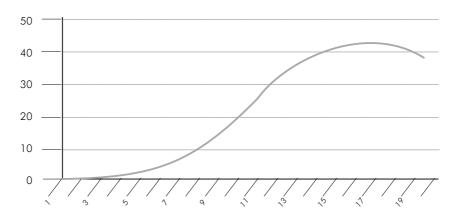


Figure 3. An Epidemic "S"Curve

As with susceptibility the concept of vulnerability may be applied at a number of levels. For example, a household with only one wage-earner who is 25 years old is more vulnerable than one in which there are two or more wage-earners, one of whom is over 50 years old. A farming system in a dry region, with rainfall limited to six weeks of the year, is one in which any shortage of labour for key cultivation activities will result in restrictions of production for the entire season. An industrial process plant that depends upon one or two key pieces of equipment, with very specialized operators who are in short supply, is more vulnerable than one where large numbers of unskilled workers are involved in the same or similar processes.

A review of some of the terms of reference for studies carried out to date shows that the researchers were commonly asked to:

- 1. assess the current state of the epidemic;
- 2. make projections as to how it might develop in future years;
- 3. assess the impact on sectors in the society and economy (typically the health sector would be included).

If studies are to maximize their value, we propose that they should explicitly identify:

- those groups who are most *susceptible* in society, in order that prevention efforts can be targeted; and
- those social and economic units (households, communities, enterprises) or sectors (welfare, health, industry, education, the military) that are most *vulnerable*.

This vulnerability may be because they will face increased demands for their outputs or services (health ministries) or because a decline in their performance will have a severe adverse effect on social and economic life. These units, areas, and sectors are drawn to the attention of policy-makers in order that the need for prevention be better understood and that the impact and its consequences be planned for.

#### Thus, impact studies should:

- 1. try to identify who in a society is susceptible to infection;
- 2. determine the likely scale of illness and death in future years;
- 3. assess the vulnerability to impact of groups in society;
- 4. make recommendations as to what can be done.

# Vulnerability to Impact: Civil Society, Social Capital, and Socially Reproductive Labour

Given the complexity of the AIDS epidemic and its long-wave nature, its impacts upon society and economy can best be understood in relation to three concepts: civil society, social capital, and socially reproductive labour.

## Civil Society: Units of Identification, Identity, Consensus and Conflict

The idea of civil society has become popular in recent years. The term is used to describe those social units that are neither part of the state nor of the household. The term refers to those social, economic, and cultural units that occupy the space between the household and the state.<sup>22</sup> The importance of the term is that it focuses attention on the large range of formal, semi-formal, and informal activities that constitutes "society". These organizations of civil society work apart from or in coordination with the state organs and, it is increasingly believed, provide the framework within which social and economic development takes place. In addition, they determine the success (or lack thereof) of such development and affect a range of other features of society, such as health, crime rates, and well-being. Civil society is supported by accumulated social capital, and social capital is a store of socially reproductive labour.

<sup>&</sup>lt;sup>22</sup> It should be noted that there is no reason at all why civil society should be or actually is conflict free. Indeed, it is often the site of considerable social and economic conflict.

Symptoms and examples of the building up and breaking down of civil society can be found in the following:

- establishment or breakdown of NGOs;
- local mobilization on issues, or increased local social conflict where people are unsure of their rights and obligations;
- establishment or failure of local and regional organizations.

#### Social Capital: Stored Trust, Understanding, and Knowledge

The term *social capital* describes the stored investments of trust and understanding that are embodied in many aspects of social life. For example, the belief that property rights will be respected and transgressors punished is taken as axiomatic in many societies. Social capital is in many respects the medium that other aspects of social and economic life require if they are to thrive. Premature loss of this kind of social capital without its replacement is a major loss to society. At a time when so much attention is paid to the importance of civil society, loss of social capital threatens the existence of civil society. However, social capital is very difficult to measure or identify.

Symptoms of the breakdown of social capital may be found in:

- failure of informal and formal caring structures as a result of overload;
- increased levels of intercommunal suspicion and failure of conflict resolution mechanisms;
- increased conflict and disputes over property inheritance and care of children on death of parents;
- failure of informal education systems such as adolescent initiation ceremonies;
- decline in child-care standards;
- decline in the informal knowledge base about values and goals of local communities and households;
- socially perceived decline in the level of meeting obligations and in honesty and commitment in day-to-day social transactions.

Symptoms of the construction and development of social capital might include:

- development of organizations to support AIDS widows;
- development of community-based organizations for the care of orphans;
- widespread perceptions of the legitimacy and fairness of police and legal apparatuses.

As was noted at the beginning of this manual, a study may have to look for impact as it may not be readily visible, and impact is a long-wave event. It is important to understand that the AIDS epidemic will affect social capital in a society. This has

long-term economic, social, and development consequences. Understanding the consequences of AIDS for social capital and socially reproductive labour may be crucial for understanding how to target alleviation strategies.

### Socially Reproductive Labour: The Work of Making Society

Socially reproductive labour is the work that goes into the production of social capital. One type of socially reproductive labour with which we are all familiar is the care and rearing of children. But there are many other types of socially reproductive labour — the work of a woman in the "informal sector" is close to "economic activity" as measured by economists, while the work of a ritual specialist is difficult to conceive in economic terms. Care of orphans is most certainly socially reproductive labour, not solely in terms of their physical care but also their emotional and social development.

Symptoms and examples of the breakdown of socially reproductive labour can be found in the following:

- perceived breakdown of caring arrangements for children and the elderly;
- perceived inadequate supply of community managers such as local councillors and leaders;
- perceived failure of informal education systems such as adolescent initiation ceremonies;
- perceived decline of child-care standards;
- perceived decline in informal knowledge base about values and goals of local communities and households.

Many of these phenomena may not be directly attributable to HIV/AIDS and may be the result of other processes. However, it is important to consider whether such phenomena are possibly associated with levels of illness and death associated with HIV/AIDS.

Impact assessments are most difficult in relation to socially reproductive labour. This manual can only hint at ways to solve the methodological problem of how changes in the quantity and quality of these issues are to be exposed through some kind of measurement. Any consideration of the effects of HIV/AIDS on these aspects of social and economic life will require sensitive analysis that takes full account of different cultural contexts and uses a combination of participatory and objective methods so as to translate anecdote and impression into data that can be measured at some level.

Long-term effects are easy to see, but we must not forget that impact studies are looking for short- to medium-term measurable effects of AIDS illness and death. While these effects may be hard to find and harder to quantify, some of the most important impacts may be longer term. Again, *they need to be looked for.* 

## Conclusion: Some Limitations of Social and Economic Impact Studies

In its early days, the HIV/AIDS epidemic was often represented in the press and other media as though it would be apocalyptic in its impact and mythical in its proportions. This has not been the case, although to the tens of millions of people whose lives it has affected the experience has been tragic and personally devastating.

### There Are No Simple Technical Solutions

Today, politicians, policy-makers, and others often expect, and are looking for, a dramatic and measurable impact from the disease – something they can respond to in a technical manner as they have respond to many other social, economic, and medical problems. There are number of reasons why this is not and will not be possible.

- The period between HIV infection and AIDS illness and death means that, although HIV prevalence levels may be high, the AIDS epidemic may not be visible.
- AIDS may not be highly visible because cases usually occur throughout the population and geographical area rather than in a single dramatic cluster (although in some rural African communities there has been a clustering of cases).
- In societies where AIDS carries stigma, cases may be even less visible as people conceal the diagnosis. An extreme case was the murder, for "bringing disgrace PPon the community", of a self-declared HIV-positive person in South Africa following a World AIDS Day meeting. In India, until recently, people infected through heterosexual intercourse were defined as "promiscuous".
- It is not clear how impact can be measured, and how AIDS impact can be disassociated from other national and international events.
- It is particularly problematic to measure the non-economic impact of the epidemic, its effects on social capital formation and on socially reproductive labour activities.

#### Thus we can conclude:

- 1. Impact stems from increased and premature levels of illness and death.
- 2. AIDS is a long-wave event that will take many years to work through a society in all its ramifications.
- 3. The epidemic progresses incrementally and silently, but in the end its impact is cumulative and is likely to be very severe.

- 4. The impact of the epidemic is not always counted by those who do the counting because the people affected may not count that is, they may be poor and marginal and part of a very large population.
- 5. HIV/AIDS is one problem among many that confront policy-makers and politicians and is less visible and more challenging than many others.
- 6. HIV/AIDS is difficult to respond to because it deals with new issues that make new demands on resources, and it requires attention to issues that government is traditionally not very good at addressing (e.g., personal behaviour, household-level dynamics and economics).
- 7. Good impact studies can encourage effective prevention programmes; good impact studies can prepare societies and economies for the worst.

### **Technical Annexes**

## Annex A. Methods of Projecting the Epidemic

Several models have already been developed for use in modelling the AIDS epidemic. These include:

- Extrapolation models, which project the future number of AIDS cases based on data on past AIDS cases. These models are simple and were used predominantly in the early stages of the epidemic before much information was available. Extrapolation models assume that trends of reported cases will remain similar to those observed in the recent past. Such models are suitable for only short-term projections.
- Projection models project AIDS cases from information on the incubation period.
   EpiModel is a good example of a forward projection model. The models are based on fairly simple assumptions, are easy to use, but are unable to simulate the impact of prevention programmes.
- Simulation models are large-scale, sophisticated, complex mathematical models that simulate interaction among individuals or population groups. They incorporate biological and behavioural variables that describe the transmission and natural history of HIV infection to simulate the epidemic. Many different simulation models have been developed. Two well-known and multipurpose simulation models are SimulAIDS and iwgAIDS\*. An important strength of these more complex simulation models is that they allow for the simulation of the effect of different intervention strategies, which can in turn be used to guide public health strategies. These models are complex and require extensive input data and a high degree of skill.
- Impact models focus beyond the direct question of projecting the number of AIDS cases and look at the impact of AIDS morbidity and mortality. Spectrum is a good example of a software package that enables the calculation of outputs such as life expectancy, infant mortality, number of orphans, dependency ratios, and health costs, among others.

## **Using Impact Models**

The Spectrum package was developed by the Futures Group International (TFGI) as a part of the policy project (a USAID-funded project). It is available from the TFGI website <a href="http://www.tfgi.com">http://www.tfgi.com</a>. This programme was designed to assist policy-makers and programme-developers and includes several programmes including the AIDS Impact Model (AIM). When used in conjunction with another programme in the suite, Demproj (a demographic projection model), AIM permits projections of the impact of the AIDS epidemic. Demproj is used to create a base population projection (assuming that there was no AIDS), and AIM is then used to create projections incorporating the impact of AIDS.

<sup>\*</sup>iwgAIDS, http://cml180.cml.edu/cml support/iwgaids.htm

Prior to using these programmes, the geographical area for which the projection will be done must be decided. The national level is most common, but regions or smaller areas can be used as long as the data are available. The base year and period for the projection will also need to be selected. The base year is often selected on the basis of data availability (e.g., a census year). The period of the projection will depend on the purpose of the projection, although it is important to bear in mind that the longer the projection, the less reliable it becomes. Once these basic parameters are decided, the data are collected and the assumptions made. Because the output of these models is by definition a reflection of the input, it is important that the data are of acceptable validity and reliability, and also that assumptions are carefully considered.

The data that are input for creating a Demproj projection include:

- the population for the base year by age and by sex (usually from a census, and preferably a census year just before the HIV epidemic began);
- an estimate of the total fertility rate for the base year and assumptions about the future total fertility rate;
- assumptions about the age distribution of fertility (often based on existing models of fertility);
- life expectancy at birth, by sex, for the base year;
- future assumptions about life expectancy, age-specific mortality (usually based on existing model tables), net migration, and the distribution of migrants by age and sex.

The input required for creating an AIM projection includes assumptions and estimates of:

- the adult HIV prevalence for the base year and projections of future HIV prevalence;
- the start year of the epidemic;
- the perinatal transmission rate (the percentage of babies who, born to HIVinfected mothers, are themselves infected);
- the percentage of infants with AIDS who die in the first year of life;
- the (adult) life expectancy after an AIDS diagnosis;
- an assumption about the percentage reduction in fertility for HIV-infected women;
- the incubation period;
- the age and sex distribution of new infections.

If projections of impacts on the economy are required, then additional input data are needed (e.g., the estimated expenditure per AIDS patient, the average number of bed days per AIDS patient, and so on). For many of these inputs, AIM provides default options that may be used. In most cases the default assumptions are satisfactory in the absence of more specific data for the region being modelled. By changing one

or more of the assumptions made, different scenarios can be created, and the impacts assessed. This enables planners to assess the social and economic value of different programmes in dealing with the epidemic.

The software itself is relatively simple to use and requires a basic familiarity with Windows software. The manuals that accompany the modelling software provide clear instructions for use. The most complex and demanding aspect of running these projections lies in deciding what assumptions to make. It is generally advisable to draw on the knowledge and experience of others who have expertise in specific areas (demographers, epidemiologists, HIV/AIDS specialists, on so on). People using this software need to be careful not to make erroneous assumptions based on simple extrapolations of the data and misinterpretation of projections. One example of misguided assumptions occurs when HIV and AIDS assumptions from developed countries are applied to developing countries, or vice versa.

The Spectrum software is effective in developing projections and displaying them in accessible graphic format, which can be useful in presentations to decision-makers. However, the software requires an informed estimate of where the epidemic is likely to reach its endemic stage, as well as the best possible data on HIV prevalence. The best approach remains developing projections as a working model that is adjusted from year to year as new data are received.

## Annex B. Imperfect Data Sets: UNDP and the World Bank

#### **UNDP**

The primary indicator produced by UNDP is the Human Development Index, which is made up of three variables: life expectancy, educational attainment, and income. It is designed to capture the concept that human development is about more than per capita income. "Income is only a means to human development, not an end. Nor is it the sum total of human lives". (*UNDP Human Development Report*, 1999) The HDI has been produced since 1990. In the 1999 report, "its methodology was significantly refined on the basis of a thorough review of its concept and formulation." The HDI for 1999 "also reflects new and improved data for 1997 for the indicators included in the HDI".

The report states that, "because of these changes, this year's HDI is not comparable with last year's. The improvements in methodology and data effect the HDI ranks of almost all countries. Thus if a country ranks higher or lower on the HDI this year compared with last year, that does not necessarily mean its state of human development has improved or deteriorated."

The report does include time series data for the HDI for five-year intervals from 1975 to 1997 (the last however being from 1990 to 1997, a seven year interval!) It will be interesting to see how comparability is maintained in the future, especially since rapid changes may result from the inclusion of HIV/AIDS factors.

#### The World Bank

Until 1998, the *World Development Report* contained a mass of statistics in its world development indicators. The institution has constantly sought to update and improve these. In 1998, the report changed, and many statistics previously included were left out. As a result, comparisons could no longer be made between countries. For example, despite the fact that Botswana has one of the fastest-growing economies on the African continent, and the most interesting social trends, it is no longer included. Instead, the user of these data is required to purchase a new document, *World Development Indicators* (in 1998, this cost \$60, a considerable expense in many developing world economies). However, even with a new, comprehensive 398-page book, the user guide states: "Selected indicators for 62 other economies – small economies with populations of between 30,000 and 1 million, smaller economies if they are members of the World Bank, and larger economies for which data are not regularly reported – are shown in Table 1.6". In other words, detailed data on 62 countries are omitted.

It is perhaps not surprising that countries like Afghanistan, Liberia, and Somalia do not have data. It is a source of concern, however, that the only data available for places like Bahrain, Swaziland, and Fiji, are gross national product, life expectancy, adult illiteracy, and carbon dioxide emissions (all "where available").

Again, as many of these countries are recipients of significant quantities of aid (per capita, this may be higher than larger countries), the decision to exclude them is a source of great concern to those who seek to use those data. It is strange that the more comprehensive indicators document should have this glaring omission.

### Annex C. OECD Development Goals

Recently the Development Assistance Committee of the OECD countries set out global development goals. It stated:

We are proposing a global partnership effort through which we can achieve together the following ambitious but realizable goals:

#### Economic well-being:

1. a reduction by one-half in the proportion of people living in extreme poverty by 2015.

#### Social development:

- universal primary education in all countries by 2015;
- demonstrated progress towards gender equality and the empowerment of women by eliminating disparity in primary and secondary education by 2005;
- a reduction by two-thirds in the mortality rates for infants and children under age 5 and a reduction by three-fourths in maternal mortality, all by 2015;
- access through the primary health-care system to reproductive health services for all individuals of appropriate ages as soon as possible and no later than the year 2015.

#### Environmental sustainability and regeneration:

5. the current implementation of national strategies for sustainable development in all countries by 2005, so as to ensure that the current trends in the loss of environmental resources are effectively reversed at both global and national levels by 2015.<sup>23</sup>

<sup>&</sup>lt;sup>23</sup> OECD, "New strategies for the challenges ahead: a changing development cooperation" http://www.oecd.org/dac/htm/stc/intro.htm

## Annex D. Commissioning Socioeconomic Impact Studies: Notes for Government Officials

Although this manual has been written for those who commission as well as those who carry out the studies, some points are of specific relevance for government officials.

- Be sure about what you want. It is crucial that you have a clear idea of what you want from your researchers and that they do not take on work when they cannot deliver. In order to achieve this, you should:
  - access existing studies;
  - negotiate the terms of reference with those who are doing the work to make sure that you are both happy with what can and cannot be done;
  - set up a steering committee or reference group to review the terms of reference, monitor progress at regular intervals, and agree on the main findings and conclusions.
- Be sure about what you are going to do with the results. If the document is to be used for advocacy, then have a mechanism set up to use it. If it is to feed into policy and planning, the best way to do this is to make sure that the results can be immediately accessed and used by the planners, and that they are in a format that can be used.
- Take an interest, and provide as much information as possible. In part, the steering committee or reference group will deal with this, but you should be able to provide the consultants with as much information as possible and open doors for them where you cannot provide this information.
- Take care in selecting your senior researchers. This type of study may require a range of technical and professional competencies. Your senior researchers should be able to provide these. Look at the team members, their past experience, and the results they have achieved on similar projects.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.



Joint United Nations Programme on HIV/AIDS (UNAIDS) UNAIDS - 20 avenue Appia - 1211 Geneva 27 - Switzerland Telephone: (+41 22) 791 46 51 - Fax: (+41 22) 791 41 87 E-mail: unaids@unaids.org - Internet: http://www.unaids.org