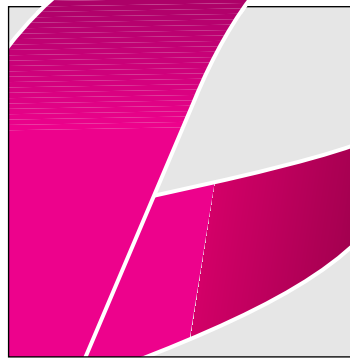


# A review of household and community responses to the HIV/AIDS epidemic in the rural areas of sub-Saharan Africa



Joint United Nations Programme on HIV/AIDS

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## Acknowledgement

*This review was compiled by Gladys Mutangadura,  
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UNAIDS  
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1999



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## Foreword

*I*n 1997 the Cosponsors of UNAIDS proposed planning a project on the impact and consequences of the HIV/AIDS epidemic to be carried out in 1998–99. Sectors to be surveyed include agriculture, children and families. The present report was initiated by UNAIDS with the cooperation of UNDP and FAO following a regional conference in Harare in June 1998 that focused on the impact of HIV/AIDS on smallholder rural households. This initiative in form of a background paper is part of the Coordinated Appeal among the Cosponsors of UNAIDS and focuses on rural areas. It takes the form of a literature survey of the information gathered so far on rural household and community responses to alleviating the HIV/AIDS epidemic with the focus on sub-Saharan Africa. Such knowledge is imperative for improving the planning of the future response in rural areas. It is crucial that we know what works and what the costs are to make it work.

The report is based on the work of Gladys Mutangadura, Duduzile Mukurazita and Helen Jackson who compiled and analysed the review on rural household and community responses to the HIV/AIDS epidemic.

In many countries and areas with a high prevalence, HIV/AIDS represents not only a health threat to the individual, and a social and economic threat to families and communities, but also destroys developmental gains acquired with difficulty over the past decades. The overall effect on society is often measured in loss of growth of GNP or lost development (points) in the Human Development Index used by UNDP. Such values/points are often abstract figures to decision makers, but such loss directly affects people when disaggregated at the household level. The effect of HIV/AIDS on households is devastating: from household surveys in Africa and Asia (Côte d'Ivoire, Tanzania and Thailand) we know that families living with HIV/AIDS have a substantial income reduction of 40–60%. This loss is compensated through spending of savings, borrowing, and reduction of consumption. These are the economic aspects; the social response strategies involve the dissolution, or part dissolution, of families: children are sent away to live with relatives; a spouse or a child migrates to earn an income; and sometimes, on the death of a spouse, the widow has to move to a brother's house.

In order to improve conditions for rural families living with HIV/AIDS and to help sustain their income base, we, the international and national decision makers and NGOs working in this field, need to broaden our knowledge of the coping strategies already being exercised by the families and communities themselves. In the process of doing this, we need to cast light on what strategies work in a sustainable way and what costs are involved in ensuring the success of such initiatives.

Hopefully, the present report will serve as inspiration for communities, NGOs and donors working in rural areas, mainly in Africa where the epidemic is not only a problem in cities or specific sub-populations, but where the disease is also taking a heavy toll on villages

and communities. The report provides examples of what strategies have worked and failed. However, it does not answer the question of the costs and effectiveness of the response initiatives as originally intended. Very few initiatives undertaken regarding the response of rural households and communities to the HIV/AIDS epidemic have been evaluated for their effectiveness and virtually none for their costs to society. It is an important finding in itself, and serves as a reminder to implementers, that few can adopt methods used by others when only the process itself is described. Process evaluation is important but not sufficient to serve as a basis for a decision of implementation. We need to know what works and why if we are to assist policy in this field.

Systematic evaluations in this field, including cost-effectiveness analyses, should be incorporated to ensure that choices are made taking into account efficiency, affordability, sustainability and equity issues when planning for the responses. It is clear from the survey that standards of impact and effectiveness are seldom defined. To ensure appropriate planning, measures of impact and outcome (in the short and long term), as well as the costs of the initiatives are needed. Such evaluations could include indicators of success such as the number of families covered by the scheme, school attendance, food security and cash availability depending on the objectives of the programme. Hopefully, this background paper will feed discussions on what can be done in rural areas to mitigate the impact of HIV/AIDS at both the household and the community level. We also hope that it will encourage policy makers and communities to monitor and document the effectiveness and the costs involved in such initiatives and so create a collective memory in this field.



## *Acronyms*

|                |   |
|----------------|---|
| <b>ABEKA</b>   | <i>Abemahamo ba Karagwe, CBO in Tanzania</i>  |
| <b>AIDS</b>    | <i>Acquired Immune Deficiency Syndrome</i>  |
| <b>ASO</b>     | <i>AIDS support organization</i>  |
| <b>AZT</b>     | <i>Azidothymidine/zidovudine</i>  |
| <b>CBO</b>     | <i>Community-based organization</i>   |
| <b>CIDA</b>    | <i>Canadian International Development Agency</i>  |
| <b>DANIDA</b>  | <i>Danish International for Development Agency</i>  |
| <b>DFID</b>    | <i>(UK) Department for International Development</i>  |
| <b>HIV</b>     | <i>Human immunodeficiency virus</i>   |
| <b>ELCT</b>    | <i>Evangelical Lutheran Church of Tanzania, Huyawa</i>  |
| <b>FACT</b>    | <i>Family AIDS Caring Trust</i>   |
| <b>FOCUS</b>   | <i>Families, Orphans and Children Under Stress Programme</i>                                  |
| <b>GASCO</b>   | <i>Gomba AIDS Care Organization</i>   |
| <b>GTZ</b>     | <i>Deutsche Gesellschaft für Technische Zusammenarbeit<br/>(German Technical Cooperation)</i> |
| <b>HIVOS</b>   | <i>Humanistic Institute for Cooperation with Developing Countries (Netherlands)</i>           |
| <b>IDS</b>     | <i>Institute of Development Studies, University of Zimbabwe</i>                               |
| <b>IGP</b>     | <i>Income-generating project</i>  |
| <b>KAKAU</b>   | <i>Kanisa Katoloki na UKIMWI, CBO in Tanzania</i>   |
| <b>KARADEA</b> | <i>Karagwe Development Association</i>  |
| <b>KISA</b>    | <i>Kisa Farm Women's Group</i>  |
| <b>KOCC</b>    | <i>Kemondo Orphan Care Center</i>   |
| <b>KOTF</b>    | <i>Kagera Orphans Trust Fund</i>  |
| <b>MACOP</b>   | <i>Missenyi AIDS Control Orphans Project</i>  |
| <b>MoHCW</b>   | <i>Ministry of Health and Child Welfare, Zimbabwe</i>   |
| <b>NACWOLA</b> | <i>National Community of Women Living with HIV/AIDS</i>                                       |
| <b>NGO</b>     | <i>Nongovernmental organization</i>   |
| <b>NORAD</b>   | <i>Norwegian Agency for Development Co-operation</i>  |
| <b>PLWHA</b>   | <i>People living with HIV/AIDS</i>  |
| <b>PSG</b>     | <i>Project Support Group, University of Zimbabwe</i>  |
| <b>ROSCA</b>   | <i>Rotating Savings and Credit Association</i>  |

|                |  |
|----------------|--|
| <b>SAfAIDS</b> | <i>Southern Africa AIDS Information Dissemination Service</i>                                  |
| <b>SAFO</b>    | <i>Society for AIDS Families and Orphans, South Africa</i>                                     |
| <b>SARDC</b>   | <i>Southern Africa Regional Documentation Centre</i>   |
| <b>SHG</b>     | <i>Self-help group</i>   |
| <b>SIDA</b>    | <i>Swedish Agency for International Co-operation</i>   |
| <b>STD</b>     | <i>Sexually transmitted disease</i>  |
| <b>STOGA</b>   | <i>St Theresa's Old Girls Association</i>  |
| <b>TARSC</b>   | <i>Training and Research Support Organization</i>  |
| <b>TASO</b>    | <i>The AIDS Support Organization, Uganda</i>   |
| <b>UNDP</b>    | <i>United Nations Development Programme</i>  |
| <b>UNICEF</b>  | <i>United Nations Children's Fund</i>  |
| <b>USA</b>     | <i>United States of America</i>  |
| <b>USAID</b>   | <i>United States Agency for International Development</i>                                      |
| <b>US\$</b>    | <i>United States dollar</i>  |
| <b>VCT</b>     | <i>Voluntary counselling and testing</i>   |
| <b>WAMATA</b>  | <i>Walio Katika Mapambano na Ukimwi, Rubya Branch<br/>(Those at War with AIDS in Tanzania)</i> |
| <b>WB</b>      | <i>World Bank</i>  |
| <b>WHO</b>     | <i>World Health Organization</i>   |
| <b>ZAN</b>     | <i>Zimbabwe AIDS Network</i>   |

## Executive summary

### Introduction

*T*he purpose of this study is to review the literature on household and community coping responses to HIV/AIDS and make policy recommendations. This paper serves as a background paper for a much shorter and more advocacy-oriented tool to stimulate discussion among the UN theme groups and the major stakeholders on what can be done in sub-Saharan Africa. This study was a desk review and analysis of relevant literature. The literature review has some limitations: because it focuses on sub-Saharan Africa, the findings may not be applicable elsewhere; and as it was a desk review, it was difficult to obtain “grey” material, which has inevitably led to gaps in coverage.

### Findings

*T*he literature review on household coping responses revealed that a variety of responses are used which can be categorized as:

1. Strategies aimed at improving food security;
2. Strategies aimed at raising and supplementing income so as to maintain household expenditure patterns; and
3. Strategies aimed at alleviating the loss of labour.

Coping strategies not requiring any cash were the ones most frequently adopted. Examples of these strategies include intra-household labour re-allocation, taking children out of school, diversifying household crop production and decreasing the area cultivated. While some of the coping responses can be reversed, some, such as withdrawal of children from school, are often irreversible. These could be viewed as short-term strategies with long-term consequences for survival.

Costs and effectiveness of indigenous household coping strategies have not been documented in research. This is clearly a knowledge gap that needs to be investigated in the future.

Policy options that can be adopted to strengthen the coping capacity of households with the impact of HIV/AIDS include:

- improving the access of households to limited resources such as labour, land, capital, draught power, and management skills;
- promotion of optimal use of available resources through improved technologies; economic support to improve incomes of affected households through income-generating activities;

- provision of self-support (empowerment) to affected groups such as child-headed households, widows, grandparents, youths, orphans, sex workers, etc., with the aim of reducing further vulnerability and strengthening their coping capacity.

Different community initiatives have sprung up to support and mitigate the impact of HIV/AIDS, driven by NGOs, religious groups, traditional healers, people living with HIV/AIDS, women, youth and others. These include:

- community-based child care;
- cooperative day care and nutrition centres to assist women cope with their work load;
- orphan support in the form of nutritional and educational assistance;
- repair of deteriorating houses;
- home care and visits to orphans and HIV/AIDS patients;
- preparation and distribution of school uniforms;
- apprenticeships and training in marketable skills to orphaned adolescents;
- agricultural projects at various levels to increase output;
- labour sharing; income-generating projects to produce food and cash;
- savings clubs and credit schemes for funeral benefits.

Community coping responses take the form of traditional grassroots or indigenous organizations such as social support groups, savings clubs and informal self-help groups, and formal community-based organizations which rely to some extent on external support from NGOs or other agencies.

Traditional indigenous groups are a major source of support in communities that are experiencing the impact of the AIDS epidemic. Literature in Tanzania, Zambia and Zimbabwe indicates that many communities have traditional indigenous groups such as savings clubs, burial societies, grain-saving schemes and labour-sharing schemes which play a major role in helping households cope with the HIV/AIDS epidemic.

In the hardest hit regions of Kagera in Tanzania, a household demographic study found that new emergency associations had specifically been formed to cope with the income and labour demands of the AIDS epidemic. The major activities done by these emergency associations include assisting with burial ceremonies, communal farming, supporting sick patients, re-building dwellings and rehabilitating farms, supporting survivors and income-generating activities. As well as providing material support, these informal groups are a major source of psychosocial support. But as the number of AIDS-related deaths increase, these existing local strategies are increasingly under pressure and there is need to design policies and programmes that are capable of providing support when existing strategies become inadequate.

Formal community initiatives include community-based organizations and AIDS support organizations which rely to some extent on external support from NGOs, governments or other development institutions. Their mitigation activities vary from country to country, but include agriculture and off-farm income-generating activities such as

handicrafts, bee-keeping, carpentry, tailoring, sewing, pig-farming, poultry-farming, banana and vegetable cultivation and building construction.

The literature also revealed that changes in community cultural norms and values have been experienced as communities try to cope with HIV/AIDS. Many communities today do not have the human and material resources to continue the culturally prescribed rituals, and rapid adjustments have had to be made. Several studies indicate that periods of mourning have been reduced substantially. Some studies also indicated changes in some traditional cultural practices which increase the spread of HIV transmission. For example, in a study undertaken in Zambia, ritual cleansing which involves sex was found to be on the decrease, particularly if the cause of death is suspected to be AIDS.

The community-based programmes which depend on external support have been responsive to the needs of those affected by AIDS, providing a much wider and more holistic package to affected and infected members. However such programmes have limitations which include: poor organizational management skills; lack of adequate funding and technical support to sustain the project when the donor pulls out; poor targeting of support; founders' problems; and, where the programme is church-funded, discrimination against non-members. Policy options aimed at tackling these problems can help strengthen the capacity of communities to cope with HIV/AIDS.

## Recommendations

The main recommendations arising from the literature review include the following needs:

- to strengthen the capacity of rural households to cope with HIV/AIDS by improving their access to limited resources; labour, land, capital, draught power, and management skills. This can be achieved by extension services promoting technologies that make optimal use of available resources, research systems developing technologies that can improve productivity given the labour and capital constraints, improving the incomes of affected households through income-generating activities, and better targeting of support to households that are highly vulnerable.
- for social assistance programmes to target a wider group of households based on both poverty and AIDS indicators. This can be achieved best by working through communities themselves in identifying the most needy.
- for policy makers and development agencies to help mitigate the impact of HIV/AIDS by working through existing indigenous traditional community mechanisms instead of displacing them. Programmes and policy should aim at strengthening indigenous responses such as savings clubs and labour and draught power clubs. In addition, there is need to closely monitor the situation in communities so that policies and

programmes can be designed that are responsive to the new challenges that arise as the epidemic progresses.

- to promote the effectiveness of community-based organizations and NGOs. Community-based coping strategies can be strengthened through the reinforcement of the management skills of CBOs and training on project design, planning, management, monitoring and evaluation.
- for meaningful partnership between the communities, governments, donor agencies, international NGOs, local NGOs, private sector and others in mitigating the impacts of HIV/AIDS.
- to intensify mitigation programmes. Multinational donors need to be more flexible in support of local initiatives with their funding, preferably by making many small grants rather than one large project grant. The present emphasis on large-scale grants and projects undermines local initiatives that may be far more effective and appropriate, as well as sustainable. Donors are, however, reluctant to have to manage numerous small projects. A mechanism is needed to resolve this problem, with perhaps an intermediate body to manage small-scale funds and report to the donors.
- for long-term government strategies to address the underlying problems which make rural households vulnerable to the impact of HIV/AIDS. Strategies should be aimed at eliminating poverty through rehabilitation and expansion of essential services such as primary education, preventive health care, clean water, sanitation, and improved access to land, credit, markets and protection against droughts through introduction of irrigation, and at creating more wage employment for the poor and landless.
- to develop a more encompassing approach to the evaluation of mitigation programmes and to ensure appropriate planning, measures of impact and outcome (in the short and long term), as well as the costs of the initiatives are needed.
- for community-based organizations and NGOs not to duplicate work that is already existent in communities but should strive for integration by supplementing or complementing community responses. External support should build on existing community structures such as churches, women's groups, schools and foster families.
- for governments to be prepared to play a more active leadership role and review their commitment to rural development. They need to undertake this with a clear analysis of the impact of AIDS on development, and of the impact of development on the AIDS epidemic itself.

## 1. Introduction

---

*I*n the past 20 years HIV/AIDS has become an increasing global phenomenon. In countries hard hit by the pandemic, morbidity and mortality have risen and are expected to continue to rise. The implications of rising morbidity and mortality are not only that HIV/AIDS is changing the demographic structure of the household but also that it is taking a heavy toll on the socio-economic well-being of households and communities. It has become apparent from research studies done mostly in the 1990s that HIV/AIDS is having an adverse impact on smallholder agriculture and therefore on the livelihoods of rural households. This alone demands attention at policy level. These socio-economic effects are largely borne by individuals, households, and communities with little, if any, support from the technology change community and policy makers. According to the 1998 report of the Joint UN Programme on HIV/AIDS (UNAIDS), more than 33 million people are living with HIV/AIDS throughout the world. Some 60% of those infected live in sub-Saharan Africa, where poverty, gender inequality and vulnerability to natural disasters create an environment that exacerbates the impacts of HIV/AIDS.

The major route of HIV infection in sub-Saharan Africa is heterosexual intercourse, estimated to account for 93% of all adult cases, followed by vertical transmission and blood transfusions. Research in developing countries on the socio-economic impacts of HIV/AIDS on households has shown the main impacts to be social, psychological and economic (see Table 1, p. 15, for a detailed listing of impacts). Rural subsistence households are often more acutely affected than urban families. They suffer loss of productive labour, loss of income, loss of food reserves, savings and assets which are diverted to meet health care and funeral costs. Additionally, educational opportunities are reduced as children are withdrawn from school to care for the sick or to do odd jobs for extra income. Reduced levels of nutrition have been found in poor households (Loewenson et al. 1997).

At the community level, as the HIV/AIDS epidemic deepens, the socio-economic impacts widen to affect the whole community, resulting in an adverse long-term effect on community structure and function. The loss of human resources affects all institutions (NGOs, CBOs) and community structures, and these losses need to be planned for. Community problems that arise include the need to support an increasing number of orphans, reduced participation of the community in neighbourhood and community structures, increased homelessness and increased crime. In other words, social cohesion is threatened, a situation that in turn increases the risk of HIV transmission.

Households and communities have already taken some initiatives to cope with the impacts of HIV/AIDS as they have done with other calamities such as drought. If they did not, they would simply cease to exist. The worst affected households are the poor



households where the impact of AIDS is to compound the problems, deepen the poverty and extend the length of the time to recover. The traditional community safety net has been weakened by the growing economic decline in sub-Saharan Africa and the increase in households in need (Tibajuka, 1997).

Very little research has been done in identifying and analysing the cost-effectiveness of the household and community coping mechanisms. The aim of this study is to document rural household and community responses to HIV/AIDS and their impact and sustainability. It will also suggest areas for potential improvement and consideration by policy makers and form the basis from which an advocacy tool may be developed. This literature review will focus on some of the following questions:

- What are the existing household and community responses to the impacts of HIV in rural areas?
- How frequent is the response adopted by different households in different localities?
- What are the costs associated with each particular type of response?
- What are the impacts (social and economic) associated with each type of response?
- How sustainable is each type of response?
- What are the emerging policy implications for future policy formulation?

Answers to these questions are crucial to policy makers and development organizations concerned with developing short-term and long-term strategies to overcome the impacts of HIV/AIDS. Without information on the responses by households and communities most affected by morbidity and mortality, few specific conclusions can be reached about the impact of alternative policies and projects.

This report is divided into six sections. Section 2 outlines the study objectives, methods and definitions of the major terms used in the study; section 3 describes current household responses to alleviate the impact of HIV/AIDS in rural areas and discusses the identified household coping strategies; section 4 identifies policy implications on strengthening the household's coping capacity; section 5 details existing community responses to alleviate the impact of HIV/AIDS in rural areas and discusses the identified community coping strategies; section 6 presents options for strengthening such strategies; and section 7 presents conclusions.



**Table 1: Potential impacts of AIDS on household**

| Potential impacts of AIDS on families   | Impact of AIDS on children   | Community stresses  |
|---|--|---|
| <ul style="list-style-type: none"> <li>- Loss of members, grief</li> <li>- Impoverishment</li> <li>- Change in family composition and in adult and child roles</li> <li>- Loss of labour</li> <li>- Forced migration</li> <li>- Dissolution</li> <li>- Stress</li> <li>- Inability to parent and care for children</li> <li>- Loss of income for medical care and education</li> <li>- Demoralization</li> <li>- Long-term pathologies (increased depressive behaviour in children)</li> <li>- Number of multi-generational households lacking middle generation will increase</li> </ul> | <ul style="list-style-type: none"> <li>- Loss of family and identity</li> <li>- Depression</li> <li>- Reduced well being</li> <li>- Increased malnutrition, starvation</li> <li>- Failure to immunize or provide health care</li> <li>- Loss of health status</li> <li>- Increased demands on labour</li> <li>- Loss of schooling/educational opportunities</li> <li>- Loss of inheritance</li> <li>- Forced migration</li> <li>- Homelessness, vagrancy, crime</li> <li>- Increased street living</li> <li>- Exposure to HIV infection</li> </ul> | <ul style="list-style-type: none"> <li>- Reduced labour</li> <li>- Increased poverty</li> <li>- Inability to maintain infrastructure</li> <li>- Loss of skilled labour, including health workers and teachers</li> <li>- Loss of agricultural inputs and labour</li> <li>- Reduced access to health care</li> <li>- Elevated morbidity and mortality</li> <li>- Psychological stress and breakdown</li> <li>- Inability to marshal resources for community-wide funding schemes or insurance</li> </ul> |

Source: Hunter and Williamson (1997).

## **2. Objectives, methods and definition of terms**

### *2.1 Objectives*

The general objective of this study is to improve understanding of mainly rural household and community responses to HIV/AIDS and the cost-effectiveness of these responses. More specific objectives include:

- identifying the household and community responses, and
- assessing the responses on impact and sustainability.

## *2.2 Methodology, scope and limitations of the study*

**T**his study is a desk review and analysis of relevant literature. It involved reviewing material in the SAfAIDS Resource Centre and in external data centres. Visits were made to the University of Zimbabwe, Institute of Development Studies, Project Support Group, UNICEF, SADC Food Security Unit, SARDC, the local UNDP and World Bank offices. The review is geographically confined to sub-Saharan Africa. Electronic data searches were done through AIDSline and Africa Health Anthology. A complete list of references reviewed for this study may be found at the end of the paper.

The study focused on literature in English obtained from sub-Saharan Africa. The diversity of different agro-ecological situations creates differences in the coping mechanisms that are adopted. No research could be located that documents costs for households or community responses. Most of the literature documenting costs pertain to preventive and care responses. Obtaining reliable data on the household economy is difficult (World Bank, 1997). Although the literature review was supposed to focus only on rural areas and the section on household coping responses reflects literature from rural areas only, the section on community coping responses reflects literature from both urban and rural areas. This is because there is a rural-urban continuum: people move frequently between rural and urban areas and community responses tend to be similar, and in some cases some types of community responses start in urban areas such as those supported by NGOs. A major limitation of a desk review is that "grey" material might not be available in resource centres.

## *2.3 Definition of terms*

**C**ommunity—a specific group of people usually living in a common geographical area who share a common culture, are arranged in a social structure and exhibit some awareness of their identity as a group (Allman et al. 1997).

**Household**—A group of persons who live in the same dwelling and eat meals together.

**Cost-effectiveness**—Cost-effectiveness is a measure of efficiency. It compares the costs of a programme with its effectiveness. A measure of effectiveness of alleviating the HIV/AIDS epidemic could be coverage of food security and of school attendance. Efforts have been made in this study to capture the documented costs and effectiveness of the different household and community strategies. However, such information has proved difficult to obtain for each of the strategies because no cost-effectiveness studies have been done on the initiatives, particularly those initiated traditionally or indigenously and because the documentation of costs of the initiatives has not been consistently presented.

### 3. Household responses to HIV/AIDS in rural areas

Households adopt a wide variety of strategies to mitigate the effects of HIV/AIDS. This section presents the types of coping strategies adopted by households, the sequencing of the strategies and their costs and effectiveness.

#### 3.1 Types of household coping strategies

There are many ways in which coping strategies can be categorized. In Table 2, we have divided them into three basic categories:

- strategies aimed at improving food security
- strategies aimed at raising and supplementing income so as to maintain household expenditure patterns, and
- strategies aimed at alleviating the loss of labour.

**Table 2: Household coping strategies**

| Strategies aimed at improving food security  | Strategies aimed at raising and supplementing income so as to maintain household expenditure patterns   | Strategies aimed at alleviating the loss of labour   |
|--|---|--|
| <ul style="list-style-type: none"> <li>• Substitute cheaper commodities (e.g. porridge instead of bread)</li> <li>• Reduce consumption of the item</li> <li>• Send children away to live with relatives</li> <li>• Replace food item with indigenous/wild vegetables</li> <li>• Beg</li> </ul> | <ul style="list-style-type: none"> <li>• Income diversification</li> <li>• Migrate in search of new jobs</li> <li>• Loans</li> <li>• Sale of assets</li> <li>• Use of savings or investments</li> </ul> | <ul style="list-style-type: none"> <li>• Intra-household labour reallocation and withdrawing of children from school</li> <li>• Put in extra hours</li> <li>• Hire labour and draught power</li> <li>• Decreasing area cultivated</li> <li>• Relatives come to help</li> <li>• Diversify source of income</li> </ul> |

The literature on the impact of adult illness and death and the way households cope suggests that individuals and households go through processes of experimentation and adaptation as they attempt to cope with immediate and long-term demographic changes. The HIV/AIDS impact in Zambia in particular and Africa in general is described as a long-wave disaster (Barnett and Blaikie, 1992; Drinkwater, 1994; Bond, 1993). Over a five-year period one episode of illness may be followed by others which gradually deplete the resources and labour supply of one or more interdependent households. The Kagera (Tanzania) study showed movements of household or family members into and

out of the household within six months prior to and soon after death and these were identified to have an important role in household coping strategies (Over, 1995). From these studies (Sauerborn et al. 1996; Donahue, 1998; Hunter et al. 1997) it was discovered that household coping mechanisms are adopted sequentially or in stages (see Table 3).

**Table 3: The three stages of loss management**

| Stages   | Loss management strategies   |
|--|--|
| <b>I. Reversible mechanisms and disposal of self-insuring assets</b> | <ul style="list-style-type: none"> <li>· Seeking wage labour or migrating temporarily to find paid work</li> <li>· Switching to producing low-maintenance subsistence food crops (which are usually less nutritious)</li> <li>· Liquidating savings accounts or stores of value such as jewellery or livestock (excluding draught animals)</li> <li>· Tapping obligations from extended family or community members</li> <li>· Soliciting family or marriage remittances</li> <li>· Borrowing from formal or informal sources of credit</li> <li>· Reducing consumption</li> <li>· Decreasing spending on education, non-urgent health care, or other human capital investments</li> </ul> |
| <b>II. Disposal of productive assets</b>                             | <ul style="list-style-type: none"> <li>· Selling land, equipment, or tools</li> <li>· Borrowing at exorbitant interest rates</li> <li>· Further reducing consumption, education, or health expenditures</li> <li>· Reducing amount of land farmed and types of crops produced</li> </ul>   |
| <b>III. Destitution</b>  | <ul style="list-style-type: none"> <li>· Depending on charity</li> <li>· Breaking up household</li> <li>· Distress migration</li> </ul>  |

Source: Donahue (1998).

After their study on strategies of coping (Sauerborn et al. 1996) with illness-related costs in rural Burkina Faso, a coping strategy sequence was developed which fits well with the stages identified by Donahue. The generated sequence was as follows:

1. Use of savings
2. Sale of assets (livestock, equipment, etc)
3. Borrowing
4. Wage labour
5. Community assistance
6. Doing nothing (on the verge of calamity).

What is important to note from the studies is the factors determining a household's ability to cope, which include: access to resources, household size and composition, access to resources of extended families, and the ability of the community to provide support.

Households that have higher incomes or better alternative resources are better able to cope with the impact of HIV/AIDS. Households with the cushion of support are more likely to recover during steps 1 or 2. Poor, small households that have no margin to absorb the extra costs of HIV illness are the most vulnerable to the epidemic. They do not have the assets, particularly livestock assets, which influence the choice of subsequent coping strategies such as borrowing or hiring labour. These households were identified to be at risk (at the verge of calamity) and require special assistance to help strengthen their coping capacity.

### *3.1.1 Household coping strategies aimed at improving food security*

#### **Reduced consumption of food, substitution with cheaper alternatives and reliance on wild food**

When a breadwinner dies, households are faced with limited food to meet consumption requirements. Rugalema (1998) in Tanzania, Sauerborn et al. (1996) in Burkina Faso, and Barnett et al. (1995) in rural Uganda, found that some households cut back the number of meals when faced with food shortages. This was also reported to be a common strategy used by households to cope with a shortfall of income from one sector or individual following an unexpected crisis in Ethiopia (Webb et al. 1992). SAfAIDS research in Zambia in 1998 found that households were buying less expensive foods as an alternative or were substituting purchased relish (a side dish served with the staple carbohydrates e.g. maize or cassava) with indigenous or wild vegetables.

#### **Begging**

SAfAIDS research in Zambia (SAfAIDS, in press) identified begging as a survival strategy in times of need. Sauerborn et al. (1996) indicates that this survival strategy is practised when the households that are at risk have been pushed into calamity.

### *3.1.2 Household coping strategies aimed to raise income*

#### **Income diversification**

Sauerborn et al. (1996) in rural Burkina Faso, SAfAIDS (in press) in rural Zambia, and Barnett et al. (1995) in Uganda, found that rural households that cannot meet their food requirements, or obtain cash, through agricultural production, undertake a range of income-generating activities such as selling firewood, brewing millet beer, selling livestock, building fences, handicrafts, tailoring, and petty trade to supplement their income. In Malawi, Munthali (1998) reports that households cope by doing ganyu (casual labour). In rural Zambia, some members of rural households were reported to have migrated to urban areas in search of employment so that they can remit some income to their rural area, while some work in neighbours' fields as casual labour so as to earn some income (SAfAIDS, in press). There are documented cases of children as young as 10 going out to work in an effort to cope with the illness of a parent (UNDP, 1997). Households that do not have the ability to diversify the source of income are particularly vulnerable to the epidemic. Prevailing poverty drives women into sex work as a source of income. In Malawi, 12-year-old girls were driven to have sex to fulfil short-term income needs (Little, 1996).

### **Sale of agricultural produce and use of savings**

In a study in Zimbabwe by Kwaramba (1997) sale of agricultural produce was reported to be a dominant coping strategy to raise income to meet additional health costs. Barnett et al. (1995) in rural Uganda, Drinkwater (1993) in Mpongwe rural area, Zambia, Rugalema (1998) in Bukoba district, Tanzania, and Sauerborn et al. (1996) in Burkina Faso, report similar findings and indicate this widely used coping strategy to be among the first strategies used. Tibaijuka (1997) in Kagera Tanzania reports that households sold bananas (their staple food) in desperation to raise money to meet medical costs. The same studies also indicate that households use up savings to raise money to meet health and funeral costs.

### **Loans**

Sauerborn et al. (1996) indicates that the informal financial sector is an important source of income used during times of need. Aryeetey and Hyuha (1990) report that households in Tanzania, Zimbabwe, Ghana, Kenya, Malawi and Uganda resort to borrowing from the informal sector for other disasters such as drought. Sauerborn et al. (1996) in rural Burkina Faso, SAfAIDS (forthcoming) in rural Zambia, and Rugalema (1998) in Bukoba district, Tanzania, Tibaijuka (1997) in Kagera Tanzania identify the informal financial sector to include:

1. relatives, friends and neighbours
2. rural cooperatives
3. rotating and savings club associations
4. rural traders and
5. rural money lenders.

Loans are given without much bureaucracy and with minimal paperwork. Interest rates are non-existent or very low for sources (1), (2) and (3), but can be substantial for sources (4) and (5) (levels higher than 100% have been reported). When interest rates are high, not all households borrow, as indicated by the following reports from a socio-economic impact study conducted in Zambia (SAfAIDS, 1997).

*"When we are stranded and have no food we borrow money from Kaloba [a 100% interest rate credit facility run by individuals]" (SAfAIDS, in press, in Zambia).*

### **Sale of assets**

Tibaijuka (1997) in Kagera, Tanzania and Rugalema (1998) in Bukoba district, Tanzania, report that households that did not have enough income to buy food or to pay for health care, funeral expenses or education costs sold assets in response to the crises. The amount and type of assets so disposed vary across households. Evidence shows that a wide variety of assets, except land, were disposed of to generate cash for use in seeking treatment. In a study by Rugalema in Tanzania and by SAfAIDS in Zambia, the range of assets most commonly sold included cattle, bicycles, chickens, furniture, carpentry tools, radios and wheelbarrows. Some households report pledging future crops to meet immediate cash needs (Rugalema, 1998, SAfAIDS, in press).

*"After mother died we were left with no means of survival. She was the one who looked after us. My brother had just completed school and could not go to college because there was no money to pay for his fees. I cannot get a job myself—jobs are difficult to find these days. We decided to sell blocks that*



were meant for extending our house. There were 500 and we sold them for K150,000.00 and used the money to set up a business. We started selling charcoal by the roadside near our house. At least we are able to have a meal a day.”

“Since I am the eldest, I started doing small jobs for people to earn something (he took on a task of becoming the head of the household). But people do not pay me in time, life is just difficult. My aunt, who used to take care of my mother, is now paying school fees for our youngest brother. I spend more time looking for money to make ends meet.” (SAfAIDS, in press).

### **The role of the extended family**

Throughout history the family, or in economic parlance the household, has formed the crucial social and economic unit on which most human societies have been based. The extended family as safety net is still by far the most effective community response to the AIDS crisis (Mukoyogo and Williams, 1991). Literature reveals that affected households in need of food send their children to live with relatives: Sauerborn et al. 1996 in rural Burkina Faso, SAfAIDS (1998) in rural Zambia, Barnett et al. (1995) in Uganda, Lwihula (1998) in Kagera region, Tanzania, Rugalema (1998), Drinkwater (1993) in Zambia, Kwaramba (1997) in Zimbabwe and SAfAIDS (in press) in Zambia. Relatives will then be responsible for meeting the children’s food requirements. However, these studies did not probe into the types of relatives, or the length of time the children stayed with those relatives. Relatives and friends may provide both moral and material support to the sick on the assumption of future reciprocation. Preparation of food, work on land or overseeing livestock will be done by another family member or neighbour in addition to their own tasks. Over time the ability of families and social networks to absorb these demands will decrease as more adults die young of HIV/AIDS.

#### *3.1.3 Household coping strategies aimed at alleviating the loss of labour*

##### **Intra-household labour reallocation and taking children out of school**

Sauerborn et al. (1996) in Burkina Faso reported that reallocation of tasks among household members was the most frequently used strategy to cope with expected production losses resulting from adult morbidity and mortality. Children may be taken out of school to fill labour and income gaps created when productive adults become ill or are caring for terminally ill patients or are deceased. In Tanzania (Rugalema, 1998) intensive use of child labour was a major strategy typically used by the afflicted household during care provision.

Although children are not directly involved in care provision they are involved indirectly, by fulfilling mothers’ and fathers’ roles in some domestic and agricultural activities (such as collecting water and firewood and harvesting crops). They also prepare food for the rest of the household, gather food, tend livestock and run errands.

Removal of children from school is a common coping strategy and was mentioned by teachers at the local primary school as one of the major factors of low school attendance among orphans and children whose parent(s) were sick (Rugalema, 1998; SAfAIDS, in press). Girls are more likely to be taken out of school than boys.

Postponement of registration at school of children of school-going age due to parental illness was also common. Whether children withdrawn from school are able to go back to school in the future is not known and this warrants research.

In some hard-hit households, young orphans might inherit considerable resources but cannot manage them. In a study in Kagera region in Tanzania, Tibaijuka (1997) found that some young orphans inherited large farms which were rapidly degenerating into bush because of lack of care. Traditionally such farms would have been maintained by the clan, but such institutions were breaking down because of shortage of labour.

### ***Hiring labour and draught power***

In Zambia, Burkina Faso, Tanzania, Malawi and Zimbabwe, affected households reported hiring labour and draught power to meet their production requirements (SAfAIDS, in press; Sauerborn et al. 1996; Rugalema, 1998; Kwaramba, 1997). Labour was hired to meet the needs of the most labour-constraining activities, namely land preparation, weeding and harvesting. However, hiring labour depends on the availability of income to pay the workers. Only households with a stable income or source of remittance were able to hire labour and draught power. Some households had to pay the labour in kind, e.g. using maize or other commodities. Poor households relied on free labour from relatives and supportive and sympathetic community members.

### ***Changing household crop production and substitution of crops***

Research in East Africa reports that households involved in any agricultural production may cultivate a mixture of subsistence and cash crops (Barnett et al. 1994; FAO, 1995). The demand for labour varies as some crops are more sensitive to timing services than others. For example, a delay in planting maize, beans or groundnuts greatly reduces yields and impacts on food security. Bananas, yams and cassava, on the other hand, do not require activity at such specific periods and can be left unattended for some time without affecting the harvest.

Extended interruption of the labour supply may also affect important activities such as land preparation or maintenance of irrigation systems which in turn affects future production. FAO studies in East Africa (FAO, 1995) have shown that affected families substituted cash crops for crops which required less labour and expensive inputs such as fertilizer and pesticides. As a result, crops like coffee were abandoned by affected households in Gwanda and Nakyerira regions of Uganda and households depended on food crops such as cassava and bananas. Tropouzis (1994) in a different study in Uganda found that widows stopped growing tomatoes, a major cash crop, owing to lack of fungicides and rice and millet, which are labour intensive, in favour of maize and cassava which require less labour. In Zimbabwe, Kwaramba (1997) found that affected households were substituting cash crops like cotton and groundnuts with maize.

### ***Decreasing area cultivated***

A socio-economic impact study (Black, 1997) in Burkina Faso and Côte d'Ivoire found that cultivated areas declined in response to labour shortages caused by illness and death in both countries. Topouzis (1994) found similar results in rural Uganda.



Depending on the price balance, households chose between food and cash crops to economise on labour. In some countries, however, innovative coping strategies have been adopted, such as sharecropping, illustrated by the following case.

*“Jane is a widow aged 45 living with her two children, a son aged 22 and a daughter of 11. She had eight children. Four died of AIDS and the others left home and married. Jane owns a coffee plot, but it has largely returned to bush because there is no labour available to maintain it. The main labour input is her own and that of the 11-year-old daughter. But she also hires some labour on a sharecropping basis and this allows some coffee to be cultivated. Having adequate land has enabled this woman to enter into sharecropping agreements with landless or land-short people. This is an effective method of coping with agricultural production in cases where there is land surplus. However, she has changed her cropping pattern, and largely abandoned coffee production in favour of food crops. She has also taken her daughter out of school to contribute more labour on the farm and to the home.”* (Barnett and Blaikie, 1992).

### **Lengthening of the working day**

Topouzis (1994), in Uganda and SFAIDS (in press) in Zambia, found that many affected households put in extra hours to make up for the labour shortages and loss of income. For example, a son with a sick mother in Zambia reported that he spends more time looking for money to make ends meet by working in the field and doing casual jobs and in addition he has to contribute an average of three hours a day towards caring for his mother and stay up part of the night attending to her needs. “The overall time allocated to tasks has increased with very little time for me to sleep” he says (SFAIDS, in press).

## **3.2 Most common coping strategies**

Coping strategies not requiring any cash were most frequently adopted (Sauerborn et al. 1996). Examples of these strategies include intra-household labour reallocation, taking children out of school, diversifying household crop production and decreasing the area cultivated. In other studies (Rugalema, 1998; SFAIDS, in press; Webb, 1992; Barnett and Blaikie, 1992) the dominant coping strategies were, in order of importance, income diversification, reduced food consumption, use of savings and sale of assets particularly livestock and household goods such as bicycles and radios.

No major variations in coping responses were documented by type of community in the literature reviewed. The literature however acknowledged that religious-based support tended to be discriminatory, supporting households that were of the same religious affiliation. Climatic conditions were a major source of variation in coping responses. Kezaala (1998) asserts that East Africa, because of its agro-ecological potential, has communities that are more resilient and can absorb a bigger orphan burden than southern Africa which is drought-prone and might have more households requiring external support because of food insecurity.

## 4. Policy implications on strengthening the household's coping capacity

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Several policy options arise out of the literature review that can be taken up to strengthen the capacity of rural households to cope with HIV/AIDS. Policy and programmes should seek to support households to overcome negative coping responses (such as withdrawing children from school) and reinforce households' positive responses. The overall aim of the policies and programmes should be to improve the short- and long-term well-being of the household in ways which do not create dependency, and to minimize the risk of household members being infected with HIV. This section presents a range of possible policy and programme options that can be adopted. There is need for country- and local-specific policies and programmes and the ones presented below merely give a broad indication of possible strategies that can be promoted to mitigate the impact of AIDS.

### *4.1 Improving agricultural production*

Since most rural households are dependent on agricultural production for their livelihood (as a source of income and food), strengthening the household's agricultural production capability is one way in which the impacts of AIDS can be mitigated. Agricultural production ability of the household can be reinforced by improving their access to labour, land, capital, draught power, and management skills, promoting use of existing labour- and capital-saving technologies, and by developing technologies that can make optimal use of the available limited resources.

#### *4.1.1 Promotion of existing labour- and capital-saving technologies*

Technology is already available that makes optimal use of available resources and can be adopted by these resource-poor agricultural systems. This technology can be promoted by extension officers for use by AIDS-affected households. This technology includes:

- inter-cropping to reduce weeding time
- promoting use of high-yielding crop varieties which are not labour-intensive
- zero or minimum tillage to reduce the need for expensive ploughs and oxen
- promoting natural pest management, thus reducing the need for expensive chemical inputs, e.g. pesticides.

#### *4.1.2 Technology development for resource-deprived households in the smallholder farming sector*

Agricultural research institutions need to consider the emerging technological needs of smallholder farmers resulting from the AIDS epidemic. In planning the technology that

will lessen the impact of HIV/AIDS, it is important that the technology proposed should be based on an appropriate analysis of the local situation. The following techniques should assist households to maintain and improve production:

- selection of the appropriate variety of crop (e.g. early maturing, disease-resistant, easily threshed or pounded)
- improvement of existing inter-crops
- concentration on high-value food crops which are drought-resistant
- the introduction of farm equipment that can be used by the weak or by donkeys (e.g. lighter ploughs and planters and a modified hoe)
- improved indigenous technologies in mulching, inter-cropping, and seed selection
- improved technologies of animal husbandry, such as cattle dipping at individual levels.

#### *4.1.3 Strengthening draught power and labour-sharing clubs*

Draught power, labour-sharing and money-lending clubs help alleviate the major constraints of AIDS-affected households, which are labour, capital and draught power. Policy and programmes that support such activities will help affected households cope with the impacts of AIDS.

#### *4.1.4 Implications of human resource losses*

To reflect the change in the rural environment, all formal and non-formal rural development institutions need to review their human resource programmes and policies. It is important that institutions respond to the AIDS epidemic by planning for the impact on labour. The central responses to the AIDS epidemic must involve HIV prevention, prolonging life and reducing morbidity from HIV: this includes creating awareness and introducing prevention policies. There is a need to plan for skills, managerial and professional losses, and to introduce multi-skilling at all levels so that rural agricultural production does not suffer unduly.

## *4.2 Income-generation and diversification of source of income*

**P**rogrammes which help improve and diversify the source of income of affected households help mitigate the impacts of AIDS. Such programmes help maintain household expenditure patterns and thus help the household avoid further losses in welfare.

#### *4.2.1 Improve households' income-generating capacities*

The first line of response should be to mitigate the impact of AIDS on households by improving their income-earning capacities (Donahue, 1998). The aim is to maintain household expenditure patterns and promote savings. This can be achieved through micro-credit projects which are typically small, short-term and rapid turn-over in nature

(such as handicraft production). Another response could be to increase the asset buffer of households by expanding their opportunities to own livestock and by protecting existing herds through good veterinary care (Sauerborn et al. 1996). For example in Uganda, Addo (1998) reported that under a project, trickle-up micro-grants of US\$ 100 were given to 30 families or a group of PLWHAs to finance non-capital-intensive income-generating activities such as knitting, weaving, gardening and fishmongering.

Economic empowerment can boost the morale of PLWHAs who have lost hope. Schemes to empower communities must specifically be targeted to women and youths who perform most of the caring work. There is need to encourage self-sustenance of such schemes through training the participants and recycling funds. Social assistance funds need to be part of a comprehensive national social policy, with well defined priorities and institutional co-ordination to ensure production of better designed projects that are sustainable. Short-term strategies do not address the most crucial problems, so there is need therefore for a combination of relief-oriented and investment-oriented strategies to ensure that, when the funds are finished, the projects can continue.

Some households depend on casual labouring as a main source of income for the family. This in turn is dependent on the creation of employment opportunities in the area. For the poorest and the landless, having access to wage employment is crucial.

#### *4.2.2 Promotion of income diversification*

Promoting income diversification can strengthen households' coping capacities. Provision of wage employment may be a strategy to provide households with additional sources of income (Sauerborn et al. 1996). In risky agricultural climates, households with more diversified off-farm income are less vulnerable to food insecurity. Another strategy is to encourage crop diversification and promote a reduction in external input requirements. Non-farm sources of income, particularly home-based income-generating and petty trading activities (after a sound analysis) are other options. Given the low success rate of IGPs in many countries, these activities should be promoted with considerable care, planning and realism.

#### *4.2.3 Schemes to finance health services*

The introduction of prepayment schemes in which payments are collected after the harvest season to cover medical costs throughout the year (Sauerborn et al. 1996) could be recommended.

### *4.3 Reducing demands on women's labour*

**T**here is need to explore ways of reducing women's work burden, through the development of labour-saving methods of food preparation and improving access to water and fuel supply. Development and promotion of efficient stoves can reduce the

time women spend collecting firewood; the time saved can be used to undertake productive activities such as harvesting, transport, storage, processing (particularly hulling and milling) and marketing of produce. In some areas the use of donkeys for transporting has helped women undertake other essential activities. Making more water points available reduces the distance walked to fetch water and can benefit women in a similar way. Some programmes aimed at providing substitute caregivers or child minders can free women to undertake other productive activities.

#### *4.4 Improving the welfare of children in need*

The effectiveness of most social programmes could be improved by targeting specific needy populations. It is only through targeted relief that desperate households can be reached. This means decentralisation and reformed screening techniques. Assistance in the form of education, health and nutrition can facilitate long-term human development. One important aspect of social assistance is the fact that poor households which are not facing AIDS need the same type of assistance as their children are also malnourished and drop out of school. Equity can be achieved if the government targets social assistance to the most needy regardless of the immediate cause of their poverty. Thus, as suggested in reviewed literature (Over, 1998; Donahue, 1998), targeting of assistance should be based on both direct poverty indicators, not just the presence of AIDS in the household.

#### *4.5 Long-term strategies*

Long-term government strategies should address the underlying problems that make rural households vulnerable to the impact of HIV/AIDS. Strategies should aim to address the following:

- health problems, e.g. through incorporating improved water and health services
- agricultural constraints, including poor access to land, credit and markets; mitigation of droughts, e.g. through introduction of irrigation
- poverty.

#### *4.6 Areas of further research*

Important gaps in knowledge have been noted on the cost and effectiveness of household responses, information that could assist programmes to mitigate the household impact of AIDS. One way of obtaining reliable household data on the impact is to include specific questions on the impact of mortality and morbidity on household income, expenditure and other welfare indicators in the current household surveys (poverty surveys, demographic health surveys or censuses). The current census or poverty survey questions do not probe the interrelationships between disease prevalence and the socio-economic status of the household.

#### *4.7 Who is responsible for the policy and programme options?*

The foregoing section has outlined a set of policy-oriented and programme-oriented recommendations but did not say whose responsibility it is to undertake a particular recommendation. The state organizations (ministries of agriculture, rural development, health, social welfare, research and extension services etc) cannot do it alone: they need to collaborate with other development agencies (such as CBOs, NGOs, ASOs) and communities if efforts to mitigate the impact of HIV/AIDS are to be successful.

## **5. Community responses to HIV/AIDS**

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Most communities have developed a wide range of complex and innovative strategies to survive the adverse impacts of HIV/AIDS. The literature revealed that in many areas, communities have spontaneously joined together to support and assist families and children affected by HIV/AIDS. The paradox is that community-based responses may be the most cost-effective interventions while being the least visible (Hunter and William, 1997). Even before the advent of HIV/AIDS, food security in sub-Saharan Africa was under threat (see Kadonya, 1998). Droughts and floods are some of the disasters with which rural communities have had to cope. African families have shown resilience in coping with disease and illnesses (Barnett & Blaikie 1992, Sauerborn et al. 1996).

Some community coping mechanisms are initiated from within the communities—one might refer to them as being indigenous or grassroots responses—and some are introduced into the communities and are financially supported by outside agencies such as NGOs, international development agencies, the government or churches. Depending on how communities are mobilized and how receptive they are to the initiatives, such projects can be successful and be sustainable when the donors withdraw. Figure 1 categorizes community responses into three broad groups that are not mutually exclusive. The responses under each group are also not mutually exclusive. For example, a community-based organization might be involved in several support and mitigation activities that include orphan support, labour-sharing, income-generating projects, and treatment and care.

According to the literature reviewed, e.g. Hunter and Williamson, (1997); Barnett & Blaikie (1992); Sauerborn et al. (1996); Donahue (1998), different community initiatives have sprung up to support and mitigate the impact of HIV/AIDS. Reviewed studies show that people affected by HIV/AIDS access help principally from family, neighbours, community institutions and local informal organizations. The World Bank Kagera study in Tanzania found that families who lost breadwinners through AIDS reported that 90% of

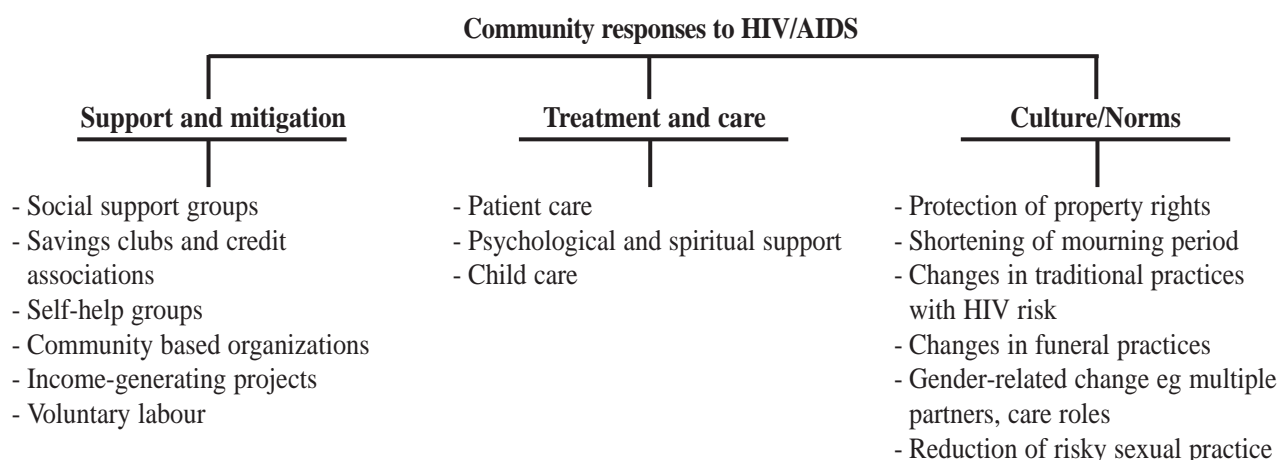


their material and other assistance came from family and community groups such as savings clubs and burial societies. Only 10% of assistance was supplied by NGOs and other agencies.

The major forms of community support and mitigation activities include the following:

- community-based child care: co-operative day care and nutrition centres to free women to work in or outside the home
- orphan support in the form of nutritional and educational support
- repair of deteriorating houses
- home care and visiting orphans and HIV/AIDS patients
- preparation and distribution of school uniforms
- apprenticeship and training in marketable skills for orphaned adolescents
- agricultural projects at various levels to increase output
- labour sharing
- income-generating projects to produce food and cash
- credit schemes for funeral benefits.

**Figure 1. Community responses towards HIV/AIDS**



Community coping responses take the form of different organizational groupings, i.e. social support groups, informal associations, self-help groups, community-based organizations supported by external development agencies, and AIDS service organizations (ASOs). While the differences between the different groupings is not necessarily clear, the first three groups tend to be grassroots or indigenous responses to AIDS by the community, where membership is by choice rather than ascriptive and the groups attempt to solve social problems through local participation, social action, resource mobilisation and building a sense of community (Altman, 1994). The other two tend to be formal grassroots organizations which rely to some extent on external support from NGOs or other agencies who act as intermediaries in the development process in which some decisions may be made externally.

ASOs is a term developed by WHO's Global Programme on AIDS to describe all those organizations other than government which provide services related to HIV/AIDS

(Altman, 1994). The following section will first present the role of the grassroots/indigenous groups which do not depend on external sources of finance, and then that of the more formal groups which depend on external financial sources.

## *5.1 Informal grassroots community organizations*

**D**ifferent forms of informal and traditional grassroots social security systems have been in existence in many societies in developing countries for a long time. Examples of such organizations include social support groups such as burial societies, grain saving schemes and labour-sharing clubs, and savings associations such as rotating savings and credit associations. Operation of such organizations is not governed by any legislation. They operate in accordance with rules agreed by the membership.

### *5.1.1 Social support groups*

Lwihula (1998) in Kagera, Tanzania, indicates that most communities have social support groups organized by men or women or both. Members of such groups support one another in routine ways, for example, by helping cultivate one another's fields, and by contributing labour, food and money to one another in times of special need (such as sickness and funerals), or on special occasions (such as marriage ceremonies). The amount of assistance such groups can provide is very small and, in the case of a death, is limited to the period of mourning. Some social support groups are formed for specific activities, for example, burial societies, grain-saving schemes and labour-sharing schemes.

Madembo (1997) in Zimbabwe, and Rugalema (1998) in Tanzania, found that burial societies are established indigenous social support organizations that provide mutual assistance to members in rural areas in the event of death and illness. They offer a measure of financial security in the event of bereavement and also cater for some of the other social needs of their members. As part of the package, burial society members also devote part of their time to assisting the bereaved by cultivating their fields.

Grain-saving schemes have a very long history in Africa's rural areas, and for many years have been used to cater for the requirements of people in the community. In Zimbabwe, Madembo (1997) and Ncube (1998) report that grain-saving schemes have been revitalized as an adapted form of the traditional system of *zunderamambo* (literally, the king's field) in which people in a community would contribute labour in the field of the chief or headman, and store the produce for when it was needed. In Zimbabwe, these grain-saving schemes have formed an important source of community support to affected households.

Rugalema (1998) in Tanzania, SAfAIDS (forthcoming) in Zambia; and Ncube (1998), in Zimbabwe, found free community labour-sharing to be a common community coping response adopted by communities to help support affected households. In Zimbabwe,



these labour-sharing schemes (nhimbe) have been in existence a long time and formed a major source of social security for households in times of disaster.

### *5.1.2 Indigenous savings associations*

Lwihula (1998) in the Kagera area, Tanzania, Ncube (1998) in Zimbabwe, and SAfAIDS (in press) in Zambia, found that many communities have indigenous savings clubs which play a major role in helping households cope with the HIV/AIDS epidemic. The major forms of indigenous community savings association are the rotating savings and credit associations (ROSCAs), and conventional savings clubs.

Madembo (1997) indicates that ROSCAs have been in existence for a long time in many African countries. A ROSCA is a group of people who agree to make contributions to a fund which is given in whole or in part to each contributor in turn; each member makes the same contribution. After everyone has had their turn in receiving the contributions, the group may disband or start another cycle. Among rural people, the contributions are either in cash or in kind (e.g. food, agricultural inputs, kitchen utensils, etc). Madembo emphasizes that ROSCAs are popular because they impose few transaction costs on members, they build mutual trust, they provide insurance and reciprocity that can be called upon in times of emergency, and they give members access to a relatively large amount of money that would otherwise be difficult to accumulate. In Cameroon, the ROSCAs have a social fund which provides life and health insurance to members (Kaseke, 1997). This is done by placing part of the contributions in a fund to be accessed as grants or loans in the event of death or sickness of members or their dependants.

In addition to ROSCAs, savings clubs are an important informal source of finance for rural households during emergencies. The funds are usually used for buying agricultural inputs such as seeds and fertilizer, for paying school fees, for buying clothing or are reserved for eventualities such as medical treatment, births and deaths. The funds can also be used as working capital in small enterprises and for starting up income-generating projects. The use of savings as security against low and uncertain incomes is the prime motive for participating in savings clubs. Most rural farmers receive their income only once a year: the savings club pool offers finance after the marketing of agricultural produce and so acts as a buffer during difficult periods.

In Zimbabwe, savings clubs have been very successful in rural areas. According to Madembo (1997) members hold a pre-savings meeting to decide what they want to save for during a twelve-month period; they then decide on their requirements for seed, fertilizer and insecticides, which are ordered in bulk to benefit from quantity discounts. Zimbabwe experienced severe droughts in the 1991/92 and 1994/95 seasons; Madembo (1997) observed that many savings club members were able to keep their children in school and also start their new investments more quickly after the rains had come, because of their prudence and the self-help orientation of their clubs. Savings clubs thus play a vital role, both directly and indirectly, in meeting the social security requirements of communal farmers.

### 5.1.3 Indigenous emergency assistance associations

The World Bank-sponsored Kagera household demographic study in Tanzania found that, in addition to the pre-existing traditional saving and mutual assistance associations, the inhabitants of many villages, particularly in the hardest hit areas (Bukoba rural, urban and Muleba districts), had launched new organizations specifically in order to cope with the costs of the AIDS epidemic (Lwihula, 1998). Lwihula's major findings (see Table 4), based on focus group discussions, reveal that:

- Traditional savings and mutual assistance associations already existed but specific organizations had sprung up in villages hard hit by the AIDS epidemic, especially among the Haya and Nyambo.
- Even households that had not yet had a member die are participating in these organizations to insure themselves because of anticipated deaths in future.
- The associations are mostly run and organized by women.
- These associations have a wide range of specific objectives and agendas (e.g. coping with crisis and burial ceremonies, and communal farming activities).
- Assistance associations among the Haya and Nyambo have regularised assistance practices (e.g. monthly meetings and contributions as insurance for imminent deaths).

**Table 4: Indigenous associations in Kagera Region, Tanzania**

| Activities  | Monthly contribution              | Size of association | Beneficiaries               |
|---|-----------------------------------|---------------------|-----------------------------|
| Mourning and burial                               | money, food, fuel, labour         | 10-40               | bereaved families           |
| Supporting sick patients                          | money, food, visits               | 10-40               | families with sick patients |
| Re-building dwellings and rehabilitation of farms | labour, money, building materials | 10-40               | families in a crisis        |
| Communal farming                                  | labour, seedlings                 | 10-40               | participating families      |
| Supporting survivors                              | money, visits                     | 10-20               | orphans, widows             |
| Income-generating activities                      | money                             | 10-40               | women's groups              |

Source: Lwihula, 1998.

Barnett and Blaikie (1992) found that informal women's counselling groups and impromptu meetings had sprung up, where women assist each other in the plantations, caring for the sick and relieving the care giver (see an example presented in Box 1). Neighbourhood women will appear unannounced to weed and trim the banana gardens of a woman who is ill. They have persuaded the local Resistance Councils to solicit outside help for the orphans and some have assumed the responsibility of caring for them in their homes. Informal counselling sessions enable women to share their experiences and concerns and "keep them sane" (Barnett and Blaikie, 1992). There is need for public space for women since it is felt that most of the public spaces available belong to men.

### Box 1: Mothers' Unions in Zimbabwe

*Many religious denominations in Zimbabwe have women's sections known as the Mothers' Union. They are guided by the principle of providing spiritual, economic and social support to those facing economic hardships. The members contribute a certain amount of money each month and the benefits range from financial assistance during funerals and weddings to visiting the sick, praying and counselling. These women's groups have been very active in taking care of children whose parents are dying of HIV/AIDS-related illnesses.*

*(From Gumbo, 1998).*

#### 5.1.4 Self-help groups of people with HIV/AIDS

In a number of African countries, AIDS organizations formed by infected and affected people play an increasing role in the response to the epidemic although the number of PLWHA involved is still tiny compared with the full scale of infection. In reality an estimated 90% of the population do not even know they are infected and of those who do know, the majority try to keep their HIV status private and do not join open PLWHA groups. In Côte d'Ivoire, the country with the highest prevalence of AIDS in western Africa, two self-help groups (SHGs) of people with AIDS were created in 1994. In other parts of Africa, some of the motivations to belong to a SHG of PLWHA are: the search for psychological, social and material support and the need to avoid stigma. Self-help groups play an important social role which includes:

- provision of services to other PLWHA;
- acting as an intermediary between PLWHA and relatives;
- HIV prevention and mobilisation among non-infected and non-affected people;
- division of labour with health care professionals;
- lobbying and advocacy (interactions with local authorities, international organizations and donors).

SHGs of PLWHA in Côte d'Ivoire and elsewhere are a collective response to an individual crisis, providing psychosocial support to people who very often are, or feel, socially rejected. Self-help groups in general have to cope with cultural and organizational problems and economic problems, as they may have little funding. A further source of that tension is that most members are poor and SHGs are regarded as a source of income. Indeed the motivation to join is often primarily an economic one, rather than a collective response to human rights violations.

It is noticeable how few middle class, affluent or professional people are active in HIV/AIDS support groups in most countries. An exception is South Africa, where NAPWA, the National Association of People with HIV/AIDS was initiated by relatively affluent gay white males, although its membership is changing. In 1998, an organization for women with HIV/AIDS was initiated by Mercy Makhamele called Women Alive National Network (WANN). This network seeks to respond to the cultural, socioeconomic and psychosocial needs of disempowered and often impoverished women and their dependants.

At the wider level, African Chapter of GNP+, the Global Network of People Living with HIV/AIDS, is based in Nairobi. Called NAP+, the Network of African People Living with HIV/AIDS, this body tries to support the role of national networks in advocacy for human rights of people with HIV.

In Zimbabwe, The Centre was established in 1994 by PLWHA to promote counselling and health services and assist the emergent Zimbabwe National Network of People Living with HIV/AIDS (ZNNP+). Now ZNNP+ has hundreds of members in support groups across the country and, as in South Africa, an independent network for women is being formed to address their needs.

The informal groups do not generally have documented records of costs or effectiveness, but they tend to have lower transaction costs because they are more informal, based on mutual understanding and involve less paperwork and organizational costs. These groups can be a major source of support in communities experiencing the impact of the AIDS epidemic by providing important inputs to agricultural production, such as labour and capital and food needs. Besides material support, these informal groups are a major source of psychosocial support.

As the number of AIDS-related deaths increase, these existing local strategies are increasingly under pressure and there is need to design policies and programmes that are capable of providing support when existing strategies become inadequate. The literature reviewed did not provide extensive empirical information on what proportion of PLWHA are members of SGHs or to what extent they can cope before they collapse. Some authors (Webb 1995; Sabatier 1997) indicate that some communities are failing to cope, particularly as far as absorbing AIDS orphans. This is particularly true in communities where the number of orphans has rapidly increased to levels which tend to overburden the community's capacity. Drought and economic decline are factors that weaken communities' coping capacity. However, the exact threshold level when a community starts to feel strained is not known, neither is the type of coping capacity that gives in first. This is an information gap which warrants investigation.

## *5.2 Formal community-based organizations*

Many of the community-based programmes assisting those affected by HIV/AIDS are developed and run by community-based organizations (CBOs). These organizations generally aim at being democratic, to represent the interests of their members, and to be accountable to them. They are formed as a response to shared experiences. In some areas where inter-household cooperation has not been the norm, NGOs have assisted the development of self-help groups which are a form of CBOs. They are usually local but can spread and grow into networks of grassroots organizations. In 1993 the United Nations Development Programme (UNDP) estimated that there were at least 100 000 CBOs worldwide (Hunter and Williamson, 1997).

Agencies working with CBOs and ASOs in some countries include ActionAid, InterAid, PLAN, SIDA, HIVOS, GTZ, DANIDA, OXFAM, European Union, Catholic Relief Services, CIDA, NORAD, UNICEF, USAID, Red Cross and World Vision. CBOs and ASOs' activities vary from country to country, ranging from home-based care through psychological support to material assistance. In the rural areas of southern Uganda, World Vision has encouraged the formation of small self-help groups engaged in agriculture and off-farm income-generating activities such as handicrafts, bee-keeping, carpentry, tailoring, and building construction.

In Kagera, Tanzania, WAMATA (a voluntary non-profit grassroots survivor assistance organization) is open to anyone who either has HIV/AIDS, or has helped to care for a relative or friend with the disease. Members contribute small amounts of money and food for some of the most needy AIDS-affected families, carry out house repairs and bring medical supplies from the local dispensary to the bedridden. However such programmes have limited local resources for sustainable services, and need external assistance in the form of food supplements, school fees, uniforms, clothing and bedding and revolving funds to enable AIDS-affected families to start schemes such as vegetable production, raising poultry and cattle, carpentry and tailoring.

In South Africa, the Society for AIDS Families and Orphans (SAFO) was formed in Soweto in 1992 to provide care and support to affected families (Gilks et al. 1998). Many CBOs depend on a number of volunteers and a few paid staff. Annex 1 shows selected self-help community groups supported by ActionAid Uganda. Annexes 2, 3 and 4 present some of the main activities of CBOs in Kagera region, Tanzania, and rural areas of Zimbabwe and Kenya, respectively.

Some CBOs have grown to become NGOs, for example The AIDS Support Organization (TASO) in Uganda. TASO started off as a small community-based organization in 1987 in Kampala, today it has expanded to six sites covering the south-eastern part of Uganda and servicing both rural and urban areas with a staff of 150 and 2 000 volunteers. TASO provides a range of services which include counselling, day-care centres for children, treatment and care, home-based care, social support such as school fees for needy children and income-generating activities such as sewing, pig-farming, and banana and vegetable cultivation. In the evaluation of TASO in 1994, treatment and care (including counselling and nursing care) were cited as the most helpful TASO services by 86% of the 619 interviewed clients, 10% indicated social support and 4% indicated other services (TASO, 1994). Its main sponsors include ActionAid, DANIDA, USAID, DFID and Australian International Development Agency Bureau.

Although it should be easier to obtain the costs and the cost-effectiveness of community-based organizations that are supported by external development agencies since they are more formal, this proved to be a difficult task. The 1994 evaluation of TASO provided no information on costs or cost-effectiveness of TASO activities. The 1998 evaluation of ActionAid's Strategies for Action community-based programmes in Uganda and Malawi also provided no information on costs or cost-effectiveness of the community-based support activities.



### *5.2.1 Child and orphan support*

Two main forms of support to orphaned children in especially difficult circumstances are institutional support such as orphanages and traditional fostering and adoption by relatives and the community. The following section first discusses programmes that are aimed at strengthening traditional fostering and care by the extended family and the community, followed by those that support institutional support programmes.

Traditionally it is assumed that the extended family and the community at large assist the household socially, economically, psychologically and emotionally. This is a common practice in most parts of eastern and southern Africa. As more households are affected by the AIDS epidemic, the literature indicates that some communities are failing to absorb all orphans from AIDS because of lack of resources, urbanisation and migration (Webb, 1997). This failure is seen, for instance, in the existence of unsupported child-headed households or, in the World Bank Kagera study, of the disappearance of some households. Nevertheless many community-based orphan support organizations have been initiated as the number of orphans increases.

The development of orphan and child care support in the community is illustrated by case studies from Zimbabwe, Malawi and Tanzania in Box 2. Where orphans do not have any extended family safety net, residential institutions or orphanages are a last resort to meet their requirements. Orphanages may be run by community churches, particularly for the under-threes, or by NGOs, government, or private individuals. As the number of children orphaned by AIDS increases, the demand for orphanages may well increase.

The review revealed that orphanages are unlikely to be sustainable on financial grounds because of the heavy, long-term burden which they place on the Department of Social Welfare or other organizations responsible for running them. According to Ainsworth and Over (1997), the cost of supporting a child in an orphanage was about eight times the cost of support in a foster home. The demanding nature of caring for infants necessitates lower child: care giver ratios in infants' homes (Powell et al. 1994). This Zimbabwe national survey of formal children's homes found that infants in homes are at a great risk of recurring infections. Powell report states that a survey of two homes with a total of 100 infants revealed that 42 infants had been admitted into hospital once and 26 had two or more admissions. It is also clear that such orphanages are rarely in the best interests of the children, either on economic or social grounds.

## Box 2: Case studies on orphan support

*In Zimbabwe, the Families, Orphans and Children Under Stress (FOCUS) community-based programme was established in 1993 in a rural area by a local church with technical support from the Family AIDS Caring Trust (FACT) in Mutare. The main activities of the project include the recruitment of volunteers from the community to identify, register and visit orphans within a two-kilometre radius of their homes. Volunteers are provided with basic training and they visit orphan households twice per month, but those orphans in greatest need, such as those in child-headed households are visited weekly. Orphans are supported materially with agricultural inputs (such as maize seed and fertilizer), primary school fees, food and blankets.*

*Other activities undertaken by FOCUS include: assistance in ploughing orphans' fields, repairing of houses, health care, child care, income supplementation and income-generating activities. The later includes the provision of material inputs to community-based projects such as poultry and vegetable gardens. Income from income-generating projects is used to support destitute families. Psycho-social support is provided through sporting and cultural activities held frequently. The FOCUS programme does not differentiate "AIDS" orphans from other orphans, and tries to target those in greatest need. They include support to non-orphaned children in exceptionally needy circumstances.*

*By 1998, the FOCUS programme had 137 volunteers in five rural sites and one high-density urban residential area in Mutare. The total catchment of the programme is 50 000 households with 1200 orphan households assisted. The total cost of the FOCUS programme is US\$ 1150 per month of which 44% is FACT administrative costs and 56% direct expenditure on the programme (78%*

*was spent on material assistance to orphans, 13% on volunteer allowances and uniforms, 9% on training and meeting costs) (Foster and Makufa, 1998). Volunteers receive minimal financial incentives: uniforms, annual Christmas gifts of US\$ 10 and training. The FOCUS programme has been replicated in some other provinces in the country and other programmes have been established in Zambia, Kenya and Malawi following visits to FOCUS sites as part of FACT's regional training programme.*

*In Malawi, the COPE programme of the Save the Children Federation USA, also stands as an example of projects designed to strengthen community capacity. The purpose of the COPE intervention is to mobilize community action to mitigate the impact of HIV/AIDS on families and children. The first phase involved setting up the programmatic strategy, which involved formation of community care coalitions that united government, religious leaders, business, community elders and other stakeholders to respond to needy families' health, psychological and economic requirements. The second phase of the programme involved strengthening the capacity of the coalitions to identify and mobilize internal resources, access external resources and organize the CBOs that would drive the initiative forward.*

*Community AIDS committees were able to identify, monitor and assist orphans and other vulnerable children by helping some return to school and providing material assistance in the form of school uniforms, clothing, maize, rice, soap and educational materials. The same community organizations were able to raise funds from community gardens, working in farmers' plots for cash, and undertaking charity walks. Orphans' guardians were assisted with agricultural inputs and technical*

*advice through the village AIDS committees. Other achievements of the village AIDS committees include the formation of youth clubs involved in promoting HIV prevention and care work, community-based child care and structured recreation activities for children. The outstanding features of this programme are the creation of partnerships between the public and private sector, and the fact that COPE acted as a facilitator in the project. At the end of the project cycle, COPE field workers were removed from villages and communities that are now said to be self-sustaining (Krift and Phiri, 1998).*

*In Malawi some CBOs have started to offer non-formal education to orphans. For example, Chifundo Orphan Home in Manase district was established by women who joined hands to help orphans continue with some form of education. The home works through the chief to identify orphans who are not attending school.*

*In Kagera region, Tanzania, 12 community-based and international NGOs assist about 47% of all orphans. External aid seems to create some degree of dependency: people or communities are likely to wait for external NGOs to come to their aid. The UKIMWI Orphan Assistance project provides limited assistance to communities to help them solve their own orphan problems. Family and community resources are mobilized, primarily to increase food production, this includes cultivation of plots and keeping two cows, and bananas/coffee cash crop farming. Other activities include organising community support to carry out housing repairs for orphans, providing school fees for a number of orphans, medical assistance for orphans, and income-generating activities for women's groups or female orphans (tailoring, needlework, basketwork and so forth). (Ng'weshemi et al. 1997)*

Mukoyogo and Williams (1991) noted that in Tanzania, by leaving their village, these children forfeit their right to inherit their parents' land and will lose their sense of belonging. They also experience poor socialization and a loss of cultural roots which proves to be very costly in the long term, as it results in maladjusted adults and perpetuation of the epidemic. Children in orphanages are not fully integrated into the community because the institutions operate in isolated communities, with integration taking place only in school (Powell et al. 1994). Targeting support directly to the community is more effective, though it is difficult for the government to determine which orphan families are most in need. CBOs have a critical role to play as discussed earlier.

### **5.2.2 Income-generating projects (IGPs)**

Local and internationally funded NGOs strive to improve the income of community members through supporting income-generating projects which will mitigate the effects of HIV/AIDS. NGOs can work through CBOs and offer assistance to either group IGPs or individual IGPs. In Uganda, CBOs with group IGPs supported by ActionAid tend to comprise members with distinct characteristics (e.g. widows, PWAs and women). On the other hand, individual IGPs are operated by individuals in the CBO. Asingwire et al. (1998) evaluated five CBOs directly supported by ActionAid Uganda which included NACWOLA, GASCO, TASO Kumi, STOGA and KISA. The IGP activities that each CBO is undertaking are presented in Table 5.



**Table 5: Income-generating project activities undertaken by CBOs in Uganda**

| Group income-generating project                                      | Individual income-generating project |
|--|--------------------------------------|
| NACWOLA  | TASO-Kumi                            |
| Rabbit rearing - Tailoring   | Goat rearing                         |
| TASO Kumi  | STOGA                                |
| Agriculture, sales of agricultural produce, restaurant, goat rearing | Revolving fund                       |
| GASCO  | KISA                                 |
| Piggery  | Revolving fund                       |

Evaluation findings by Asingwire et al. indicate that the rabbit rearing IGP does not seem to be a worthwhile venture for PLWHAs. NACOWLA is a national NGO formed in 1991 by women living with AIDS. At the time of the evaluation by Asingwire et al. the IGP had been in existence for about 10 months, and no member had yet benefited in terms of income although they had expended time, money and labour on rearing the rabbits. Despite this limitation, there were some advantages in that the group offered strong psychosocial support to people living with HIV/AIDS.

The goat-rearing scheme operated by TASO-Kumi was found not to benefit PLWHAs either, because of the nature of the project. It takes two years before a PLWHA can profit from the sale of the goats, and as beneficiaries received very young goats this placed a heavy burden on the PLWHA raising the goats. Many PLWHAs might be ill or dead before realizing a profit.

The KISA revolving fund scheme was a failure because the loans were too thinly spread among many members. However, the fund in STOGA was a success story which provided important lessons for other CBOs. Members of STOGA agreed not to spread the loan too thin by adopting a formula of just a few initial grants. These few members, all women, were able to return the loan installments in time for the other members to get their turn. In addition, the group has a drama outreach programme which earns some money, which is shared. If a member completely fails to pay, she gets less during the shareout as the rest is retained to recover the defaulted amount.

In their findings Asingwire et al. found that group projects tend to have problems as no one was specifically responsible for projects. Group projects should nevertheless be encouraged among PLWHAs because of the satisfaction they derive from the projects and the benefit they receive from meeting together and sharing their experiences. Asingwire et al. recommend that individual IGPs should be encouraged among people who are not PLWHAs. Individuals are in a position to monitor themselves and are more likely to offer total commitment to their "own" projects rather than that of a group. Experiences of IGPs in Malawi are similar, as shown in Box 3.

In Uganda, one scheme, the "Zero Grazing Heifer Project", provided families with an expectant cow, so that they could benefit from the milk production. The family fully own

the cow after it has given birth to a female calf which is taken away to continue the cycle. While the project was a success under loan circumstances, an indivisible item such as a cow may actually increase the vulnerability if the recipients are forced to make a distress sale when faced with calamity (Kezaala and Bataringaya, 1998).

### Box 3: ActionAid's experience with income-generating projects in Malawi

*In 1996 ActionAid Malawi established a pilot project targeted at orphans, the chronically ill and people living with AIDS. With funding from UNICEF, ActionAid provided capacity-building to CBOs to facilitate the formation of functional revolving savings and credit schemes. The grant funds and the small loans could be used for IGPs involved in:*

- *small-scale manufacturing and production like tailoring, baking, weaving, leather craft and food processing*
- *agricultural activities e.g. poultry, egg and broiler production, vegetable growing, etc*
- *service business, e.g. shoe repairing, bicycle repair, running of tea rooms*
- *petty trading–vending, hawkers, small retail outlets, and the selling of various food commodities e.g. beans, and maize*
- *fishing*

*Members of a functional group can get loans as a group or as individuals and are expected to repay their loans promptly to keep the fund revolving. The initial amount loaned out was Malawian Kwacha (MK) 400 but later members could receive up to MK1500.00 per person. The support group decides the maximum amount that can be borrowed on the basis of the beneficiaries' capacity to pay back the money. Money is lent out without any form of collateral required. Interest is charged at rates ranging from 10% to 20% per annum. Repayment periods vary from group to group. The recovery rate of loans has been good. A Zomba woman doing stone crushing repaid her loan IGP within a month and got a bigger loan which has enabled her business to grow. A number of CBOs like NASO in Nkhotakota have recovered 85% of*

*all loans that were given to individuals and are in a position to give out second loans.*

*Achievements of the project objectives included reaching 3000 orphans in 756 households, benefiting 62 people living with HIV/AIDS who have received funds to run IGPs, and management and IGP training for the volunteers managing the support groups. The major problems experienced included complaints that the loans were too small for the type of business that some of the beneficiaries wanted to venture into, and some of the beneficiaries did not have enough skills to run IGPs but have now gained some knowledge and skills.*

*The major lessons learnt include:*

- *Individual IGPs are better managed than group IGPs as there is greater control when a single person is responsible for managing the IGP.*
- *Income-generating activities that are locally administered by the community using their own regulations are more beneficial and less costly. It is important for communities to own their own credit schemes as this ensures sustainability.*
- *A savings and credit programme that relies upon community participation and a spirit of voluntarism has greater chances of sustainability than one that relies on a public servant for daily operations.*
- *A programme that targets the family unit will be more responsive to the needs of the ultimate beneficiaries.*

*Adapted from: Khonyongwa (ActionAid Malawi) (1998).*

In rural areas of Zambia, coping strategies are related to farming activities and brewing beer. Because of poor markets there is less buying and selling of commodities. Community small-scale agricultural schemes are managed with the profits going to those most in need, as identified by the project committee (Webb, 1995).

In their Mpongwe field study in Zambia, FAO found that livestock loans are an important intervention that strengthen household and community coping responses, especially for women. Microcredit is deliberately packaged to attract female clients, because they have shown better repayment rates worldwide (Hunter and Williamson, 1998). Experience has also shown that women are more likely to use their income to help meet children's immediate needs.

There were no documented costs and effectiveness of income-generating projects in the literature reviewed. Evaluation of income-generating projects by Asingwire et al. in Uganda in 1998 did not document any costs and effectiveness of the IGPs. According to Sabatier (1997), AIDS NGOs have poor economies of scale and administrative and overhead costs take up the biggest part of their budgets, sometimes resulting in less than 20% of the budget actually reaching the intended beneficiaries. This has been found to be true for highly personalized support such as home care (considered in the next section), counselling and crisis support. Having the programmes more community focused makes the projects much cheaper and more effective. A similar lack of data has been found in the literature with NGOs involved in mitigation work. Some particularly group-oriented types of income-generation projects have been reported to offer more psychological benefits than material ones. IGP schemes were shown to improve self-esteem as members were too busy to indulge in self-pity (Julian et al. 1996).

Some studies emphasise the need to evaluate carefully the relevance of any income-generating projects before they are introduced to the community to see whether they are relevant to community skills and resources. Evaluation of a vanilla agricultural project in Mukono district, Uganda, revealed that the project was not viable owing to the lack of a market (Kezaala et al. 1998). Lack of relevant skills and knowledge was identified in several studies to be the major reason for failure. "Good intentions, a small injection of capital and a few quick lessons cannot turn out successful tailors, poultry farmers and bakers" (Jackson et al. 1993). Interventions that are well evaluated, are low-cost and are built on community resources, skills and needs have higher chances of success, but Jackson et al. warn of the difficulties inherent in establishing successful IGPs based on cost-effectiveness and income generating criteria alone. If cost-effectiveness is not the goal, then this should be clear to all participants to avoid mistaken assumptions and false hope.

### *5.3 Treatment and home-based care programmes*

Home-based care programmes for people with HIV/AIDS or integrated with other health needs are rapidly expanding in sub-Saharan Africa as a response to HIV/AIDS. This is because of the inability of hospitals and other formal health institutions to cope with the increased demand at the same time as their real budgets are in decline because of

economic structural adjustment measures. At its worst, home care equates to home neglect, but at its best, it helps patients live through their illness and die in some dignity and comfort in familiar surroundings with their family around them. Osborne et al. describe various models of home care (from hospital outreach to NGO-led schemes to CBO and PLWHA-led ones) and discuss their relative merits. They and others (e.g. Woelk et al. 1997) note that the key difficulties facing home care concern costs and long-term sustainability, quality of services, and coverage. Foster et al. (1993) estimate that in the best schemes, under 10% coverage is likely to be achieved, and it is often less. The first home-care programmes in Uganda, Zambia and Zimbabwe were developed by hospitals but it was found that 75% of the hospital staff time was spent travelling to patient's homes in the rural areas which was very costly for the hospitals.

The WHO-sponsored study of 1993 (WHO, 1994) in Zambia found out that the average cost of a home visit by a three-person team was US\$ 26, and concluded that home care was a costly, capital-intensive service but that it could become more efficient if communities were allowed to play a major role. In a different study Gilks et al. (1998) also concluded that hospital-run home-based care units were not cost-effective since they were expensive and could not cover all the those in need. In the early 1990s, hospital-based home-care programmes began to work more closely with community-based volunteers from churches and other social groups. The community home-based programmes, which involve local volunteers in home visits, are more cost-effective and the community-based teams are able to spend more time with patients than hospital-based teams.

The home-based care study in Zimbabwe by Woelk et al. (1997), albeit based on a small and not necessarily representative sample, found the cost of community home-based care to be substantially higher in rural areas than urban areas, mainly because of increased transport costs (US\$ 42 per visit in rural areas compared to US\$ 16 per visit in urban areas). Salaries and transport costs accounted for the greatest part of the costs (ranging from 78% to 90%). The authors concluded that it is essential to increase the involvement of communities and to develop the sense of community ownership of programmes so as to minimize costs.

Many community home-based care programmes take the form of medical and nursing care, material assistance, as well as emotional, spiritual and social support. However, there is a basic assumption that resources will be available to meet the drugs and material requirements. This might not be the case in resource-poor rural areas and might be a major obstacle for the functioning of the community home-based care programmes. Another major obstacle is when the number of people requiring home-based care rises to levels that outstrip the capacity of the community home-based care service.

Gilks et al. (1998) indicate that costs for the Chikankata home-based care programme in the rural area of Zambia were about US\$ 1000 per client served. The largest costs were transport costs. Chikankata hospital is a Salvation Army-supported hospital, serving a rural population of about 100 000 people. In comparison, the costs of the Catholic Diocese Copperbelt home-based care programmes in Zambia are modest in relation to

the number of beneficiaries. An analysis of programme costs (excluding orphan support) in the township of Ipusukilo over a 24-month period in 1996–98 found that the average expenditure per month was US\$ 2216 for 400 patients, or 3600 people including household members. The largest single item was welfare support (food, clothing, blankets, bed sheets) for families which accounted for 39% of money spent, followed by drugs and equipment which accounted for 21% (Blinkhoff et al. 1999). Evaluation of home-based care programmes in Zambia is shown in Box 4, and the conclusion of the study described is that community-rooted home-based care can make the programme much cheaper, reducing substantially the staffing and transport costs and allowing the greater proportion of the funds to go as direct service benefit to patients and families.

### *5.4 Changes in cultural norms and values*

In the African context, as more and more people die of AIDS, communities have to forgo traditional mourning practices. Many communities today do not have the human and material resources to continue culturally prescribed rituals and rapid adjustments have had to be made. African funeral rituals usually involve bringing the body into the home for at least one night, washing it, a public viewing, a graveside service, a big meal for the mourners and a week-long period of mourning in which friends and relatives sleep in and around the house of the deceased (McNeil, 1999). Several studies indicate that periods of mourning have been reduced from seven to two or three days for an adult and from three to two days for a child (Lwihula, 1998; SAfAIDS, in press; Kilonzo et al. 1996). In Uganda, the custom of showing respect when a neighbour dies by not working in one's garden for four days has been dropped. "You cannot afford to do that now or else you will have no food" -Dr D Kabatesi, head of the Theta AIDS-education Project (McNeil, 1999).

Some studies also indicated changes in some traditional cultural practices that used to increase the spread of HIV transmission. For example, in a study undertaken in Zambia by SAfAIDS (in press), ritual cleansing involving sexual intercourse after a woman is widowed is now on the decrease, more so if her late husband's cause of death is suspected to be AIDS. Instead ritual cleansing now involves putting a beaded ring around the waist of the widow, and smearing her with mealie meal. The widow should not get married or have sex, lest she dies or goes mad, until the ring drops off on its own.

Some communities have made efforts to protect the property and inheritance of widows and children from being appropriated by the family of the deceased spouse by working together with community leaders.



#### Box 4: Cost and effectiveness of home-based care in Zambia

*In Zambia, AIDS is already the most common cause of death for adults admitted to hospital. Total HIV infection projections for 1998 are as high as 1.8 million, or nearly 28% of the total population. The vast majority of those infected will seek health care at some point in their illness, causing demand for hospital beds to increase by as much as 20% annually in the next decade. PLWHAs are expected to occupy 90% of the country's 25,000 hospital beds by 2010.*

*Forty-seven home-based care programmes have been set up since 1987 to provide services for PLWHAs in their communities. Further, the Zambian government has responded by formally endorsing home-based care as a part of its health strategy, urging district health boards to support home-based care and encouraging home-based care programmes to improve efficiency through increased integration with other community health care systems.*

*A study has been carried out to examine some home-based care programmes initiated by hospitals and communities. Broad comparisons were made between these two major types of infrastructure to explore their relative efficiency and success in integrating into existing health care services. Unit cost per home visit varied significantly, ranging from US\$ 10 to US\$ 40 for the hospital-initiated programmes (due to the difference in structures, services and productivity of these programmes) to US\$ 2 for a community-based programme. Major costs include transport, supplies, salaries and training. Hospital costs varied between US\$ 3 and US\$ 8 per day, although neither costs incurred by visiting family members nor loss of opportunity costs could be calculated.*

*The key conclusion of the study is that, although external financing is required, support for the home-based care movement in Zambia should be continued and increased. Home-based care programmes in Zambia have been exemplary and an inspiration to the rest of the world. They have clearly brought immeasurable comfort and service to thousands of PLWHAs, their families and communities. Nevertheless, there is an urgent need to improve the efficiency and lower the cost associated with current home care services as carried out in some countries.*

*Increased use of home care could alleviate some of the pressure on tertiary care centres. Costs can be lowered by avoiding vertical programmes based on outreach activities which require vehicles, have low coverage and demand a great deal of senior staff time. The demand for hospital care could be diverted to community care, if the existing primary care facilities located closer to households were to be better utilized and supported, including the availability of comprehensive care. Communities would be able to organize and offer a broader spectrum of clinical as well as emotional and spiritual support. To accomplish this, however, the capacity of communities and families to care for PLWHAs will need to be increased and made more sustainable. Often, as shown in the case studies, capacities are available but underutilized and not linked together, such as church groups, local health workers, traditional healers, caring by family members.*

*Source: Ng'weshemi et al. 1997.*

## 6. Policy implications on community coping responses

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*R*ural communities that are coping with increasing losses due to HIV/AIDS draw on the existing family and community for support. They are sharing their experiences of how to cope with HIV/AIDS losses with other communities. Service organizations and NGO support help bring in resources that are required particularly for treatment and home-based programmes. The literature has shown how people are mobilizing themselves using traditional and modern systems of care in order to provide support to the sick and the disadvantaged in their communities. People living with HIV are playing an increasing role in the community.

The outstanding strengths of traditional grassroots community responses are that they cost less, are based on local needs and available resources and the mutual understanding of community members. The main limitation of these grassroots initiatives is that they do not generate enough resources to buy drugs and other treatment and care requirements, so their support in this aspect is rather limited. In addition they may place a heavy work load on women who already work long hours.

The literature has shown that, as the numbers of AIDS-related deaths increase, the existing community strategies are increasingly under pressure. This observation underscores the importance of closely monitoring the coping capacity of communities so that policies and programmes can be designed that provide support in strategic ways to maximize the effectiveness of local initiatives and help them to continue. External support by health planners, policy makers, donors and NGOs should support community-rooted initiatives and not replace them. The need for sustainable approaches that can reach the growing number requiring support and ensure a basic quality of service makes it essential that effective community mobilization and development form the cornerstone of strategies for care. HIV prevention efforts should be an integral element of these strategies if the emphasis is on openness and community recognition and ownership of the problem. This also requires the creation of a non-discriminatory legal and human rights framework in which people with HIV/AIDS feel secure in disclosing their situation.

The community-based programmes that are dependent on external support have been very responsive to the needs of those affected by AIDS. The responses supported by such programmes were much wider and more holistic than others and included support to orphans, improved life skills such as training youths, home-based care (nursing care and drugs), income-generating projects and counselling. However, such programmes also have limitations which include poor organizational management skills; lack of adequate funding and technical support to sustain the project when the donor pulls out; poor targeting of support; founder's problems; and, sometimes when the programme is church-funded, discrimination against non-members.

Some policy options arise out of the literature review that can be taken up to strengthen the capacity of communities to cope with HIV/AIDS. This section presents a range of possible policy options that can be adopted.

### *6.1 Enhancing and mobilizing community capacities*

As indicated in an earlier section, families depend on the extended family, neighbours and informal community groups for much of their support. It is important that programmes and policy aim to enhance and mobilize capacities that exist within communities. The pandemic is placing enormous strain on the traditional coping mechanisms of the extended family, steadily eroding the extended family's capacity to care for those suffering from or bereaved by HIV/AIDS. According to a 1997 study by McKerrow in Zimbabwe on the willingness of communities to absorb orphaned children, families are more willing to care for orphans if some form of support is offered, for example free education, free health care and food supplements (Michael, 1998). It is therefore important that programmes and policy are aimed at enhancing and strengthening the traditional coping responses of extended families and their communities.

NGOs and CBOs can greatly increase the effects of their resources by facilitating and strengthening the autonomous AIDS responses of communities, rather than attempting direct provision of services. This can be achieved by supporting activities that are owned by communities such as child care, non-formal education and labour sharing, providing programme ideas and seed funding to community groups, by supporting informal societies so that they can expand to bring in new members and by building community capacity to undertake these responses through the provision of training and technical assistance to community volunteers. Churches and women's groups are willing to help but lack the resources and skills to make orphan visiting programmes work (Foster and Makufa, 1998). However, before making any intervention an external change agent (whether it be government or NGO), should conduct a thorough situation assessment to determine community needs and survey the existing responses. The change agent should build on existing responses to the crisis, seeking to strengthen and not to replace or eliminate initiatives already underway.

### *6.2 Strengthening community responses*

Community responses to AIDS can be strengthened in a number of ways. These include:

- the democratization and localization of resource allocation;
- reinforcement of the management skills of CBOs;
- training on project design, planning, management, monitoring and evaluation;
- the establishment of a forum for NGOs and CBOs to exchange their views and experiences;
- building links between donors, NGOs, CBOs, and the government.

Again, sound community mobilization and development strategies including participatory rural appraisal (PRA) are essential.



### *6.3 Mitigation support*

In a survey of 75 NGOs in six selected countries in sub-Saharan Africa (Cameroon, Côte d'Ivoire, Kenya, Tanzania, Zambia and Zimbabwe), the United States National Research Council found that, while on average 65% of the selected NGOs indicated AIDS prevention as one of their goals or objectives, only 32% mentioned mitigation of the impact of AIDS as their goal. Of the NGOs who did, the breakdown of the mitigation interventions provided for all countries was: counselling 50%, community awareness 11%, economic assistance and self-help projects 34%, and training 5%. These results suggest that mitigation is not receiving the support and attention that it deserves. Particularly in some hard-hit countries, increasing numbers of households require mitigation support.

The literature review revealed that there is a need to have a combination of relief and mitigation activities. Even in a community with very low HIV/AIDS prevalence, there is a need to set up mechanisms to respond to locally identified determinants that may increase vulnerability to HIV/AIDS and to work towards strengthening community responses to reduce that vulnerability. Of major importance is the issue of timing of support to strengthen household and community responses. Affected households which are failing to cope because of the youth of the head of household or the lack of land or other basic assets need relief support to help them from entering permanent destitution. Once signs of recovery appear, relief support can be gradually replaced with mitigation support for longer-term needs. The emphasis should be on helping families avoid jeopardizing long-term survival to meet short-term needs, the most obvious examples being withdrawal of children from school and sale of remunerative assets.

Communities are best placed to identify needy families, vulnerable children and orphans. There is need, therefore, to involve communities in developing systems to enumerate and assess the needs of families and children, to determine the extent of problems, to raise awareness, and to promote informed decision-making (Donahue, 1998). Communities are also best placed to monitor and maintain contact with children, supervise their activities, and prevent child labour abuses. Support is more effective when channelled to the poorest families and orphans to prevent them from falling into permanent destitution. Given the large and growing numbers of orphaned children where the epidemic is mature and severe—and the poverty prevailing in many countries—it is important that countries develop an orphan policy that seeks to integrate orphans in national development. Orphan policy will help collaborating organizations identify and target resources to affected children, monitor their progress and protect their rights.

### *6.4 Income-generating activities*

It is still questionable how income-generating projects can be feasible and sustainable in severely constrained economic environments where markets are scarce. But specific income-generating activities can be very effective when participants already have the

necessary skills and access to resources and markets. Efforts by outsiders to introduce unfamiliar income-generating projects incur significant costs and fare poorly.

In developing interventions to improve income-generating capacities, it is important to recognise that the composition and vulnerabilities of households differ and change over time, as do their capacities. Their potential to participate in and benefit from economic and other interventions depends to a large extent on how children and adults use their time and whether they can make time for additional activities. Activities that help reduce demands on household members' labour so as to free them to undertake other productive activities are the most valuable. However, women risk being doubly affected by engaging in some income-generating activities since they are also expected to provide community care. It is, therefore, important to evaluate carefully the impact of particular policies and programmes to ensure that they do not overburden women. Projects that supplement or complement existing coping mechanisms can become sustainable. Interventions that are low-cost and community-centred have a higher chance of success.

An important objective needs to be the development of employment. For the poorest and the landless, having access to wage employment is crucial, in both rural and urban settings.

### *6.5 Working in partnership*

Policy makers and programme planners should recognize that HIV/AIDS is not only a health problem but a development crisis, with an impact not only on community members' health but on nearly all aspects of community development. Policy and programmes that seek to benefit HIV/AIDS-affected families should be multi-sectoral, linking the government, religious groups, NGOs, the private sector and the community in endeavours aimed at improving cooperation in supporting and strengthening community-based responses. If government is committed then there should be evidence of support both at national policy level and involvement at local levels. The government is expected to play the leading role in creating an environment conducive to the promotion of sustainable development in the rural areas. All formal government organizations (Ministries of Agriculture, Education, Health and others) could play a bigger role if they reform their policies and programmes to respond to the needs of the HIV/AIDS-affected households. These government departments can achieve this by reviewing the existing policies and programmes and replacing them with ones more responsive to the epidemic, and showing political and economic commitment for AIDS intervention. They need to contribute and show commitment for promoting, among others, adequate services to affected households through human resource capacity assessment and capacity building of agricultural and rural development institutions while reviewing their policies on a continual basis so that emerging challenges posed by HIV/AIDS are taken into account.

Donors can help NGOs and CBOs to engage in longer-term planning and capacity building. Multinational donors need to be more flexible with their funding in support of

local initiatives, preferably by making many small grants rather than one large project grant. The present emphasis on large-scale grants and projects undermines local initiatives that may be far more effective and appropriate, as well as sustainable. Donors are, however, reluctant to manage numerous small projects. A mechanism is needed to resolve this problem, with perhaps an intermediate body to manage small-scale funds and report to the donors. It is strongly recommended that avenues be explored to achieve this.

### *6.6 Measuring effectiveness of community responses*

Meaningful cost and benefit analysis should be undertaken so that the actual costs of community and household responses are estimated. This could help in selecting and strengthening cost-effective responses that will yield the greatest benefits to communities. Given the current economic crisis experienced by developing countries, resources for HIV/AIDS mitigation are on the decrease and funds from many donors are on the decline. It is essential that mitigation responses by communities are closely monitored and evaluated so that the greatest impact is achieved with the limited resources available.

## **7. Conclusions**

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*I*n the past 15 years, the HIV/AIDS epidemic has placed severe stress on households and communities. The increase in morbidity and mortality is taking a heavy toll on the well being of individuals, households and communities. The epidemic has greatly affected access to education and health services, fulfilment of basic needs such as food and housing and the right to privacy and human dignity. Yet people throughout the world have mobilized themselves to confront its challenges (Williams et al. 1995).

A variety of coping responses have been deployed by households to mitigate the impact of the pandemic. In general terms, some of the coping responses adopted by households have been found to render households insecure and vulnerable. Sale of assets, withdrawal of children from school, reduced food consumption and use of savings and investment, all have negative impacts on the future well-being of the family. On the other hand, some household coping responses have positive impacts on the long term well-being of the household, such as income diversification, share-cropping, adoption of labour saving technology such as inter-cropping and diversification of crop production. It is therefore important that policy and programmes are designed in such a way that the positive household responses are reinforced while at the same time households are discouraged from adopting coping responses that can compromise their future well-

being. For example, agricultural research policies can be geared towards development of appropriate technology suited to low-resource conditions, and the planning of rural development projects that can support orphans, create employment, and promote household food security.

The community responses documented in this literature review demonstrate how communities have developed traditional and modern responses to help meet the urgent needs of people with HIV/AIDS. The responses have included: labour sharing, orphan support, community-based child care, repair of deteriorating houses, home care and visits to orphans and HIV/AIDS patients, preparation and distribution of school uniforms, apprenticeship and training for orphaned adolescents to give them marketable skills, income-generating projects to produce food and cash, and credit schemes for funeral benefits. Traditional community coping mechanisms are limited to activities that do not demand substantial amounts of financial resources such as buying drugs and other treatment and care requirements, and the literature revealed that if the whole community is impoverished due to AIDS, community coping responses can be overburdened. But if measures can be taken to prevent the spread of the infection or to intervene before community resources are stretched to breaking point, they can be much more effective in the long run.

Community-based organizations that receive financial support from external agencies have been very beneficial to many affected households, although they do have some limitations that need addressing. If these community strategies are adapted to local needs and take into account locally available resources, they can be applied to other developing countries. Community-based organizations and NGOs should try not to duplicate work that is already existent in communities but should strive for integration by supplementing or complementing community responses. External support should build on existing community structures such as churches, women's groups, schools and foster families.

If programmes are to be effective it is also important to target households that are most in need. However, targeting AIDS-affected households only is unethical, since it may leave out households that are equally in need for other reasons. It is, therefore, important that programmes target a wider group of households based on both poverty and AIDS indicators. This can be achieved best by working through communities identifying the most needy themselves.

Without investment in human development, there is no long-term progress in national development, stability and the skills base to overcome development obstacles. Government alone cannot achieve the basic well-being of the entire national population. This calls for meaningful partnership between the communities, governments, donor agencies, international NGOs, local NGOs, private sector and others in order to address the problems of HIV/AIDS successfully. But governments should be prepared to play a more active leadership role and review their commitment to rural development. They need to undertake this with a clear analysis of the impact of AIDS on development, and of the impact of development on the AIDS epidemic itself.

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- Vancouver Conference Abstracts 1996
- Geneva Conference Abstracts 1998
- Southern African Network of AIDS Service Organizations (SANASO) Abstracts 1997
- African Health Anthology
- World Wide Web Internet searches and databases

### **Resource Centres**

- SAfAIDS
- World Bank
- UNDP
- SADC Food Security Unit
- SARDC
- University of Zimbabwe Department of Economics
- UNICEF
- ActionAid
- Save the Children UK
- Ministry of Health and Child Welfare
- Health Economics and HIV/AIDS Research Division, University of Natal, Durban

### Annex 1: Selected self-help groups in Uganda

| <i>Name</i>      | <i>Location</i> | <i>Activity</i>   | <i>Type of group</i>         | <i>Year when support started</i> |
|------------------|-----------------|---|------------------------------|----------------------------------|
| <b>Kisiizi</b>   | Rukungiri SW    | Home-care, counselling and sensitization                        | Hospital and community-based | 1994                             |
| <b>Kuluva</b>    | Arua North      | Home-care, sensitization, testing                               | Hospital and community-based | 1995                             |
| <b>BWC</b>       | Rukungiri SW    | Sensitization, counselling                                      | Women's group                | 1995                             |
| <b>STOGA</b>     | Nebbi North     | Drama, IGA  | Women's group                | 1995                             |
| <b>AEGY</b>      | Kamuli, East    | Youth, sensitization, IGA                                       | Youth group                  | 1994                             |
| <b>YAAC</b>      | North, Apac     | Youth, drama, sensitization                                     | Youth group                  | 1995                             |
| <b>SED</b>       | Central         | Counselling and family life education                           | Catholic church              | 1994                             |
| <b>Kisa</b>      | North, Nebbi    | Sensitization for youth in school                               | Teachers' group              | 1995                             |
| <b>TASO Kumi</b> | East            | IGA, Home care, counselling                                     | NGO                          | 1994                             |
| <b>EUDO</b>      | Central         | Sensitization for youth in school                               | NGO                          | 1993                             |
| <b>GASCO</b>     | Central         | Counselling and sensitization                                   | Community placed             | 1995                             |
| <b>THECA</b>     | Central         | Sensitization and training of traditional healers               | NGO                          | 1997                             |
| <b>NACOWLA</b>   | Central         | Women's group, PLWHA group with a national remit and doing IGAs | National PLWHA women's group | 1997                             |

Source: Asingwire et al. 1998.

## Annex 2: Survivor assistance organizations in Kagera, Tanzania

| <i>Organization</i>  | <i>Date started</i> | <i>Target group(s)</i>          | <i>Programme interventions</i>                       |
|----------------------|---------------------|---------------------------------|--|
| <b>ABEKA</b>         | 1987                | Orphans                         | Food, education, health, home-based care             |
| <b>Huyawa (ELCT)</b> | 1991                | Orphans, families               | Food, education                                      |
| <b>KAKAU</b>         | 1990                | Orphans, widows, elderly        | Prevention, education, health, food, home-based care |
| <b>KARADEA</b>       | 1987                | Orphans, AIDS patients, elderly | Income-generation                                    |
| <b>KOCC</b>          | 1991                | Orphans                         | Food, education                                      |
| <b>KOTF</b>          | 1988                | Orphans, caretakers             | Food, education, health, home-based care             |
| <b>MACOP</b>         | 1991                | Orphans                         | Food, health, home-based care                        |

Source: World Bank, University of Dar es Salaam (1993)



### Annex 3: Examples of CBOs in rural areas of Zimbabwe

| <i>Organization</i>                                | <i>Date Started</i> | <i>Source of Funding</i>    | <i>Target Population</i>                          | <i>Activities</i>  |
|--|---------------------|-----------------------------|---|--|
| <b>Chabwira Sewing Club</b>                        | 1993                | Donations                   | Affected families                                 | Income generating through trading of clothes, emotional support, training on counselling, sewing |
| <b>Chorovakamwe PLWHA Support Group</b>            | 1993                | FACT and FASO               | Affected families, people living with HIV/AIDS    | Sewing, vegetable production, home care services   |
| <b>Kumutsirana Support Group</b>                   | 1994                |                             | People living with HIV/AIDS and affected families | Sewing, knitting, poultry raising, emotional support, information sharing                        |
| <b>Regina Coeli Mission Hospital Support Group</b> | 1994                | Regina Coeli Mission        | People living with HIV/AIDS and affected families | Income-generation, sewing and knitting, emotional support and information sharing                |
| <b>St Peter's Mission Hospital Support Group</b>   | 1994                | St Peter's Mission Hospital | People living with HIV/AIDS and affected families | Sewing and knitting, emotional support, home care and information sharing                        |
| <b>Tshelanyemba AIDS Care and Prevention</b>       |                     | SAT                         | Affected families                                 | Soap making, jam making, emotional support, information sharing and practical assistance         |
| <b>Usizo Kuzulu Support Group</b>                  | 1994                |                             | People living with HIV/AIDS and affected families | Income and emotional support, information sharing and home-care service                          |

Source: SAfAIDS, ZAN (1995) Harare.

#### Annex 4: Examples of CBOs in rural areas of Kenya

| <i>Organization</i>                                 | <i>Target population</i>   | <i>Activities</i>  |
|---|--|--|
| <b>AKADO HIV/AIDS Interventions</b>                 | People living with HIV/AIDS; women; the aged; rural communities  | Advocating for HIV/AIDS issues, clothing distribution, general HIV/AIDS education, HIV/AIDS counselling and testing, home-based care, information services, support services                 |
| <b>Anti-drugs movement for better living</b>        | People living with HIV/AIDS; children; rural communities   | General HIV/AIDS education; IEC materials distribution; training on specific issues.   |
| <b>Busia Young Men Christian Association (YMCA)</b> | People living with HIV/AIDS; children; orphans; youth; people with disabilities; trainers; rural communities; community development workers  | Advocating for HIV/AIDS issues, condom distribution; day care for children; general HIV/AIDS education; IEC material distribution; training of trainers; HIV/AIDS education through theatre. |
| <b>Catholic Diocese of Homa Bay</b>                 | People living with HIV/AIDS; youth; women; men; widowed; rural communities; urban communities; community development workers; health workers | General HIV/AIDS education; IEC material distribution; training non-health professionals   |
| <b>CDC/KEMRI</b>                                    | Rural communities  | General HIV/AIDS education; HIV/AIDS counselling and testing; HIV/AIDS education through theatre   |
| <b>Community Initiatives Support Services</b>       | Rural communities  | Capacity building; bereavement support services; general HIV/AIDS education  |
| <b>Msamaria Community Health Youth Group</b>        | Orphans; youth; women; hospital patients; rural communities; community development workers   | General HIV/AIDS education; HIV/AIDS counselling; day care for children; home-based care for PLWHA; training of health and non-health professionals  |

Source: Kenya AIDS NGOs Consortium (1998).

**Notes:**

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.



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