



Praxis Paper No. 13

# The Organisational Impacts of HIV/AIDS on CSOs in Africa

*Regional Research Study:  
Uganda, Malawi, Tanzania*

By Rick James

with Brenda Katundu, Betsy Mboizi,  
Emily Drani, Daudi Kweba and Rogers Cidoso



# The Organisational Impacts of HIV/AIDS on CSOs in Africa

## *Regional Research Study: Uganda, Malawi, Tanzania*

By Rick James with Brenda Katundu, Betsy Mboizi,  
Emily Drani, Daudi Kwebwa and Rogers Cidosa

Keywords: HIV/AIDS, economic costs, civil society, NGOs, Malawi, Uganda, Tanzania

### **Executive Summary**

HIV/AIDS is having a silent but significant impact on the organisational capacity of civil society organisations (CSOs) in sub-Saharan Africa. HIV/AIDS increases internal costs due to higher medical and insurance expenditure, and reduces productivity through the loss of valuable staff and management time for sickness, care and funerals. This impact might be so severe as to threaten the very survival of many CSOs over the next few years. To date, we have had no information as to how serious a problem HIV/AIDS is for CSOs. Consequently, neither CSOs nor their donors are really talking about it openly, and appear to be doing little to build organisational resilience to the disease.

A three-country research study was designed to address this knowledge gap through a collaborative effort by INTRAC; the Capacity Building Unit for NGOs (CABUNGO), Malawi; the Community Development Resource Network (CDRN), Uganda; and the Organisational Development Training and Facilitation Centre (TRACE), Tanzania. This research assessed the economic and social costs of HIV/AIDS infection for the organisational capacities of selected CSOs in Malawi, Tanzania and Uganda.

The findings enable local CSOs and international agencies throughout Africa to better predict strategic and budgetary implications of HIV/AIDS. They reinforce and corroborate the results of an initial pilot which took place in Malawi in 2005 (James and Katundu 2006). While the quantitative figures are based on respondents' own estimates, and therefore should be treated with some care, HIV is clearly affecting CSOs in these three countries:

- 62% of the CSOs had experienced at least one staff death in the past 5 years
- 72% of CSOs suspected that one or more of their current staff were HIV+
- Yet CSOs were considerably underestimating the extent of staff infections.

Working in a context of high HIV prevalence is costing CSOs more money to achieve fewer results. Respondents estimated that their staff budgets would increase by an average of 7%, and that performance would reduce by 10% (through staff being absent or distracted from work). The most serious costs of having HIV+ staff were extra medical costs, reduced

office morale, the need to repeat work, and sick leave. The most serious costs of having staff affected by HIV were the psychological distress of looking after dying family members, time off for funerals, and the extra management time that responding to HIV/AIDS involved. It is even possible that the real impact is worse than the figures suggest, as relatively conservative assumptions were used in the calculations.

CSO leaders are particularly affected by HIV, as they have to take responsibility for sickness in their extended families, their communities and also their organisations. There is a significant gender dimension to these costs, as working women are expected to perform the cultural roles of care and support as well as providing financial support.

Some CSOs are responding to the situation, but in limited and informal ways – for example:

- providing some support through existing general medical schemes and pensions
- allowing staff time off for caring, visiting the sick and attending funerals – but few of the CSOs actively monitored and managed absences
- providing HIV awareness training for staff – although these were usually *ad hoc* and one-off
- drafting an HIV policy – although only 25% had finished the drafting process, and only 10% were implementing the policy.

None of the respondents had undertaken impact and risk assessment or strategic human resource planning; had developed systems to measure or manage the impact; or had budgeted comprehensively. Few CSOs had approached donors to cover the extra costs of responding to HIV/AIDS. Some were even apparently changing policies and procedures to avoid paying the costs.

Such a considerable organisational impact, and such a limited CSO response, raise critical strategic issues for CSOs. The future prediction for many countries in sub-Saharan Africa is that the impact of HIV/AIDS will become worse. The survival of CSOs is at stake. Yet HIV/AIDS provides an opportunity. It is exposing many of the inconsistencies and anomalies in both CSOs themselves, and the aid system as a whole. HIV/AIDS has such extreme costs that the only way to build resilience is to implement the good management practices and donor practices that have been voiced so easily in the past.

An appropriate local CSO response to HIV needs to:

- start with leadership, ensuring that leaders are committed to the process
- consider the organisation's values and culture – an effective response to HIV requires a culture of openness and responsibility
- look to the strategic implications inside and outside the organisation – it should integrate external and internal mainstreaming responses
- build on informal systems and be appropriate for the stage of the organisation's development
- develop responsibility at all levels, including the individual level
- not equate the response to HIV with just policy – it is about strengthening whole organisations, not just the HIV component

- not equate HIV policy development and implementation
- invest in staff awareness and prevention and, where possible, link with others for more resource-intensive treatment and care programmes
- actively learn from others' experiences in this field
- look for long-term resourcing, including individual contributions, but also ongoing support from donors.

International non-government organisations (INGOs) and donors cannot remain comfortably on the sidelines as their partners struggle with the disease. They must become actively involved in assisting their partners to respond in a strategic and cost-effective way if they are to remain relevant in the region. The coalition of Dutch NGOs working with the STOP AIDS NOW! Project are showing how this can be done (Holden 2006).

Working in a context of high HIV/AIDS prevalence will cost partners more money to achieve less output. However unpalatable, donors must adjust their plans and targets. It will require donors to invest not just in capacity building, but also in simple capacity maintenance. Donors will also have to change their ways of working, moving beyond the project mentality to take much more seriously the responsibilities that come with partnership. For many CSOs, their survival will require that development rhetoric and jargon finally become reality.

## **Acknowledgements**

To CORDAID: for providing enlightened financial support, not just to this research, but also to the critical cause of mainstreaming HIV in their partners in sub-Saharan Africa.

To CABUNGO, CDRN, TRACE: for undertaking the crucial fieldwork. Co-researchers in this work (Brenda Katundu, Betsy Mboizi, Emily Drani, Daudi Kwebwa and Rogers Cidosa) worked extremely hard to gather and analyse the data. They went much further than 'the extra mile'. We trust this research will bear fruit in changing both organisations and individual lives.

To INTRAC: for considerable support to the research design and write-up (Kasturi Sen and Katie Wright-Revolledo). They have revised it critically for substantial intellectual content. Rebecca Wrigley has also given important management support to the whole process as well as editorial input.

# Contents

<b>Executive Summary</b>	<b>i</b>
Acknowledgements	iv
Acronyms	vi
<b>1 Introduction</b>	<b>1</b>
1.1 Background	1
1.2 Regional Research Project	2
1.3 Structure of this Praxis Paper	2
<b>2 CSOs' Experiences of HIV/AIDS in Malawi, Uganda and Tanzania</b>	<b>4</b>
2.1 National Contexts	4
2.1.1 Malawi	4
2.1.2 Uganda	4
2.1.3 Tanzania	5
2.2 Overall Impacts on CSOs	5
2.3 Economic Impacts of HIV/AIDS	7
2.3.1 Economic Impact of HIV-Infected Staff	8
2.3.2 Economic Impact of Staff Affected by HIV in their Families	11
2.4 Gender Impacts	12
2.5 Influence of Organisation Type	14
<b>3 CSOs' Responses to HIV/AIDS</b>	<b>16</b>
3.1 How are CSOs responding to HIV?	16
3.2 Why is there a limited response from CSOs?	19
3.2.1 Constraints at Individual Level	19
3.2.2 Constraints at Organisation Level	20
3.2.3 Constraints at National Level	22
3.3 Insights from International NGOs and the Private Sector	23
3.3.1 Examples of Good Practice	23
3.3.2 Learning Points from INGOs and the Private Sector	24
<b>4 Ways Forward</b>	<b>26</b>
4.1 How Should CSOs Respond?	26
4.2 How Should Capacity-building Providers Respond?	27
4.3 How Should International NGOs and Donors Respond?	28
<b>5 Conclusions</b>	<b>31</b>
References and Bibliography	33
Appendix 1 Research Methodology	35

## **Acronyms**

CSO	civil society organisation
FBO	faith-based organisation
ILO	International Labour Organization
INGO	international non-government organisation
NGO	non-government organisation
PLWHA	people living with HIV and AIDS
TRACE	Organisational Development Training and Facilitation Centre (Tanzania)
VCT	voluntary counselling and testing
WHO	World Health Organization

# 1 Introduction

## 1.1 Background

We now know the impact of HIV/AIDS on Africa. More than 3 million people are dying each year from HIV-related illnesses. Attrition from HIV/AIDS has slashed the average mortality to less than 40 years in many sub-Saharan African countries (WHO 2005). With 5 million new infections in 2005, predictions for the next decade are even worse. No wonder commentators are warning: 'Development becomes virtually impossible in the era of AIDS' (Barnett and Whiteside 2002). The Millennium Development Goals will remain a pipe-dream for many.

Most major donors have prioritised funding for HIV/AIDS. There has been a laudable emphasis on mainstreaming HIV externally into programme work with communities. But much less attention has been paid to the impact of HIV on the organisational capacity of partners (Holden 2003; James 2005).

Any organisation working in a context of high HIV/AIDS prevalence will face increasing internal costs from higher medical and insurance expenditure, and from reduced productivity through the loss of valuable staff and management time for sickness, care and funerals. African civil society organisations (CSOs) are not immune from these impacts – indeed, the age profile of their staff and the travel required for work makes CSOs more susceptible to the impact of HIV. Despite the global emphasis on HIV/AIDS, these debilitating costs to organisations are still largely ignored, by both Northern donors as well as African CSOs themselves. We are, in effect, living in 'organisational denial' of HIV/AIDS.

The extra financial costs of HIV/AIDS to organisations are rarely budgeted for, and are usually silently absorbed into other budget lines. This makes CSOs' work appear expensive and increasingly inefficient. In addition, the likely loss of staff is rarely factored into human resource planning, making already fragile CSOs even more vulnerable. Business as usual is not a tenable option. If CSOs are to survive this pandemic, they need to adjust their strategies, management systems and financial budgets. In an increasingly competitive aid system, this is no small challenge.

There are a number of factors constraining CSOs' responses (James 2005), but one of the most basic is that CSOs and their donors have no real idea about the extent of the economic or social cost of HIV/AIDS to their organisations. Nor do they know the amount they need to invest to implement an effective response. Limited record-keeping in many CSOs makes it very difficult to analyse trends in absenteeism, sickness, and increased medical costs. Fear of job loss means that colleagues cover up for absenteeism, camouflaging the actual costs. CSO leadership fears that addressing HIV/AIDS will dramatically increase budgets as the organisation takes responsibility for paying for family access to anti-retroviral therapy for life. As a result, the extra costs due to HIV/AIDS, and the added costs of internal HIV/AIDS mainstreaming, are very rarely factored into donor budgets. As donors place increasing emphasis on CSOs meeting results-based targets, this may undermine CSOs' attempts to obtain funding in the future.

In this context INTRAC, with the Capacity Building Unit for NGOs (CABUNGO), Malawi; the Community Development Resource Network (CDRN), Uganda; and the Organisational Development Training and Facilitation Centre (TRACE), Tanzania, embarked on a joint research project to assess the economic impact of the HIV/AIDS pandemic on CSOs in these countries. This project builds on an initial pilot that was carried out in Malawi (James and Katundu 2006).

## 1.2 Regional Research Project

INTRAC coordinated a three-country study<sup>1</sup> with field research undertaken by researchers from CABUNGO in Malawi, CDRN in Uganda and TRACE in Tanzania. The research drew on the combined experience of each organisation in assisting local CSOs to develop appropriate organisational responses to HIV/AIDS. It aimed to:

- assess the economic and social costs of HIV/AIDS infection on the organisational capacities of selected CSOs in Malawi, Tanzania and Uganda
- provide information to enable CSOs throughout Africa better to predict the strategic and budgetary implications of HIV/AIDS.

Ten NGOs in each of Malawi and Uganda, and nine in Tanzania, were selected for their diversity of size, age, type and leadership. The researchers used the same semi-structured questionnaire to interview about four members of staff from each NGO ( $n = 112$ ), always including the Director, the Finance Manager, and the person responsible for human resources. Recall was the primary data-gathering method used. Eighty-four respondents also completed a leadership impact-monitoring questionnaire, to quantify the personal impact on them as leaders and track gender differentials. Semi-structured interviews also took place with three INGOs and two private-sector companies in each of the three countries. This was for comparative purposes, to find out what was possible and good practice in each context.

In addition to gathering information, the research process itself proved to be a valuable capacity-building process. It created the space for people to stop and think about an issue they felt was *'too frightening to contemplate'*. The exercise not only prompted people to check their own lives, but has also already prompted some to respond within their organisations.

## 1.3 Structure of this Praxis Paper

This paper<sup>2</sup> is written for staff of development agencies working, and supporting others to work, in areas of high HIV/AIDS prevalence. If we are to work effectively, we need to know how HIV affects organisations, and what can be done to build organisational resilience to it. We hope that, through this paper, people will be challenged to apply the strategic implications to their own organisation, whether as a donor, a capacity builder or an implementing NGO.

---

1. The full methodology of the research is found in Appendix 1.

2. This Praxis Paper has largely been taken from the regional research report. A full copy of the report is available from [rjames@intrac.org](mailto:rjames@intrac.org)

Chapter 2 explores the experience of CSOs with HIV/AIDS in Malawi, Uganda and Tanzania. It analyses the quantitative impact of both the direct and indirect costs of HIV/AIDS estimated by respondents, and describes both the extra financial burden of HIV to CSOs and the loss of staff time and consequent drag on performance. Section 2.5 analyses the gender dimension to these costs. Section 2.6 examines whether organisational variables (such as size, age, faith base, gender of leadership, HIV focus) have any influence on organisational costs.

Chapter 3 focuses on CSO workplace responses to HIV/AIDS, asking how aware CSOs are of the current situation. Section 3.2 analyses how CSOs are responding by organisation type. The response of the private sector and INGOs is described in Section 3.3. Section 3.4 analyses some of the factors that are constraining CSOs' responses.

Chapter 4 looks at the ways forward. In the light of the costs and constraints, recommendations are made to CSOs as to how they can respond appropriately and effectively. Section 4.3 addresses the implications for capacity-building providers, and section 4.4 looks at donors. The conclusion summarises the findings of the paper and addresses the specific objectives of the research.

## 2 CSOs' Experiences of HIV/AIDS in Malawi, Uganda and Tanzania

### 2.1 National Contexts

The three countries in the study are among the poorest in the world, and are experiencing generalised<sup>3</sup> HIV epidemics. Their socio-economic and demographic status means they are likely to feel the effects of HIV more than better-off countries. Table 1 outlines key indicators from 2003.

**Table 1: Socio-economic statistics for national study sites**

Country	HDI rank (out of 177 countries)	Life expectancy	GDP per capita (US\$)	Percentage of population under-nourished	Percentage of population earning <US\$1 per day	Under-5 infant mortality (per 1000 births)
Malawi	165	39	605	33	42	178
Uganda	144	47	1457	19	–	140
Tanzania	164	46	621	44	20	165

Source: UNDP (2005).

#### 2.1.1 Malawi

Malawi is the poorest country in the world that is not in, or emerging from, civil war. It has about 11 million inhabitants. Sixty-five per cent of the population are living at or below the poverty line (Malawi Poverty Reduction Strategy Paper 2002). Life expectancy has dropped to just 39 years. According to WHO (2005), Malawi has a generalised heterosexual epidemic that is not stabilising. Overall, the national rate of infection among adults (15–49) years is estimated at 14.2%, but with greater prevalence in urban areas. The rate in Blantyre, where the research was conducted, is estimated at 27.6%. HIV/AIDS is now the leading cause of death in the most productive age group, resulting in 86,000 deaths annually.

#### 2.1.2 Uganda

Uganda is perceived as one of the AIDS success stories in Africa. It is the country in the region that is most open about AIDS. HIV prevalence has fallen from 18% in 1992 to 7% in 2005 (WHO 2005). This decline may be attributed to the nationwide prevention campaign and political will, resulting in behavioural change, especially with regard to the use of condoms. But WHO also calculates that 5% of the decline is simply due to increased mortality – dead people no longer count as infected (WHO 2005:25).

Almost 1 million Ugandans (of the total population of 27 million) have already died from AIDS (currently about 80,000 per year). AIDS is the leading cause of death for those aged 15–49 years. In 2004 there were still 530,000 people infected (UNAIDS, UNICEF, WHO 2005c). Life

3. A high level of infection in the whole population.

expectancy has fallen to 47 years. Kampala, the research site and capital city, has the highest prevalence rate, 8.5%.

### 2.1.3 Tanzania

Tanzania has a total population of about 34.2 million, with 40% living in absolute poverty. Life expectancy at birth, currently 46 years, is likely to fall to 40 by 2010. According to WHO (2005), 'Tanzania is a high-burden, low-income country facing one of the largest HIV epidemics in the world'. The current adult HIV prevalence in Tanzania is estimated at 8.8%. This corresponds to approximately 1.6 million people. The prevalence of HIV/AIDS in the urban centres, where this research was conducted, is 13.5% in Mbeya and 10.5% in Dar es Salaam. For the past 10 years, prevalence in these urban cities has been increasing.

## 2.2 Overall Impacts on CSOs

In all three countries, HIV was generally believed to affect staff more junior than the interviewees (although national statistics show that HIV rates are higher among professionals and the more wealthy). When asked about deaths among staff and dependents, one CSO Director avoided mentioning that his own wife had recently died, saying there had just been sickness among watchmen. Yet most people interviewed were sufficiently knowledgeable about the disease and its symptoms to make a reasonable judgement about whether or not someone has AIDS. They were able to estimate how many staff had died, and how many were infected (Table 2).

Sixty-two per cent (18/29) of CSOs in this study have had a staff member die of suspected HIV-related sickness in the past 5 years. This figure is far worse than the 7.5% of CSOs in Natal, South Africa identified by Manning (2002). Respondents estimate that HIV-related sickness accounts for the vast majority of staff deaths (Table 3).

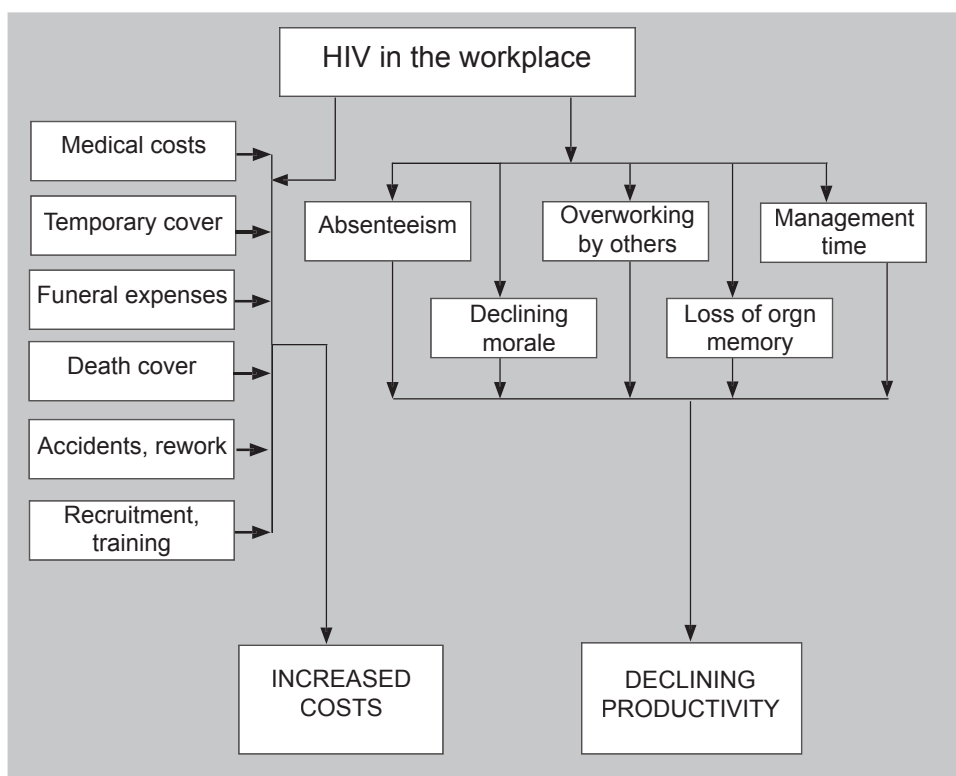
**Table 2: Staff deaths from suspected AIDS**

Country	Number of CSOs with HIV-related staff deaths	HIV-related staff deaths	Non-HIV-related staff deaths	Percentage of HIV-related deaths
Malawi	7/10	33	2	94
Uganda	7/10	20	3	87
Tanzania	4/9	6	2	75

**Table 3: Suspected HIV+ staff in CSOs**

Country	Number of CSOs with suspected HIV+ staff	Number of staff suspected HIV+ (from interviews)	Number of staff likely HIV+ (from urban prevalence)
Malawi	9/10	24	100
Uganda	10/10	27	21
Tanzania	2/9	2	18

**Figure 1: Increased costs and declining productivity in organisations**



Almost every CSO involved in the study in Uganda and Malawi believed they had HIV+ staff and will therefore incur organisational costs as staff develop AIDS. For Malawian respondents, this is likely to be an underestimate of the extent of HIV among their staff. If prevalence among CSO staff is average for their city, there will be 100 HIV+ staff in the sample, but they estimated only 24. This underestimate is far worse in Tanzania. Despite the AIDS deaths recorded in Table 2 above, Tanzanian CSOs still deny the likelihood of HIV infection among staff. This mirrors research among CSOs in South Africa (Connelly 2005).

Overall, HIV/AIDS leads to increased costs and declining productivity in organisations (see Figure 1).

Respondents estimated that HIV/AIDS is having a very significant economic cost (Table 4). Where costs could not be attributed solely to HIV, the assumption of 70% in Malawi and

**Table 4: Financial impact of HIV/AIDS on CSOs**

Country	Direct cost of HIV per person (US\$)	Direct cost as percentage of staff budget*	Declining productivity (%) <sup>†</sup>
Malawi	398	10.2	-9.0
Uganda	357	6.1	-10.7
Tanzania	168	4.6	-9.6

\*Direct costs have been calculated by aggregating: medical costs, insurances, temporary cover, funeral expenses, death cover, accidents or rework, recruitment or training.

<sup>†</sup>Declining productivity has been calculated by aggregating staff time lost through HIV-related absenteeism, and estimated impact of the cost on performance from overwork on others, management time, declining morale and loss of organisational memory.

Uganda and 50% in Tanzania was used (Appendix 1). It must be stressed that these are estimates, not definitive answers, thus these findings should be seen as tentative and treated with caution. But they do represent the best estimates of a cross-section of senior managers (including the Director and Finance Manager) in each CSO.

The impact of HIV on CSOs in terms of both direct and indirect costs is considerable and has serious strategic implications. CSOs are spending significantly more on medical costs, insurance, pensions, replication of work, accidents, funeral costs and staff cover as a result of having staff infected with HIV. This averaged US\$336 extra per person per year in the three countries – an increase in the staff bill of between 5 and 10% due to HIV/AIDS. CSOs' overheads are therefore considerably higher than before, and worse than the hypothetical predictions made by Manning (2002). These averages conceal important variations, with some CSOs obviously much worse affected.

The increase in direct costs is only part of the equation, however. Working in a context of high HIV/AIDS prevalence led to loss of time through staff being sick; taking compassionate leave to look after sick relatives; being absent from work to attend funerals; and taking up valuable management time as a result. This has a direct impact on the performance of CSOs. Despite the contextual differences, there is surprising similarity among the three countries studied as to the indirect impact of HIV. They estimate that HIV/AIDS consumes staff and management time and consequently reduces performance by around 10% per year.

This 10%, however, might be an underestimate. The numbers were calculated based on responses to interviews using reasonably conservative assumptions. The respondents were only rarely able to quantify any decline in performance that comes from the impact of the more indirect, organisational costs such as:

- increased stress and overwork for remaining members of staff
- knock-on effects for other staff of a key staff member being absent
- worry and distraction at work due to sick relatives
- loss of organisational memory when a staff member dies
- undermining their vital relationship with beneficiaries, donors and clients.

Working in a context of high HIV prevalence will cost CSOs more money for less output. But there is still little recognition of this among stakeholders. Such findings are the antithesis of what the aid system is currently demanding – 'more impact for less money'. The danger is that, unless something is done soon, CSOs will gradually lose trained and experienced staff, which will compromise their performance further. Beneficiaries and donors will be dissatisfied with services. Overstretched staff may take a more instrumental approach to their work – just working for the salary. The pressure on leadership will increase, reducing opportunities for good practice. Good CSO leaders – a scarce and mobile resource – may lose heart and either manage more autocratically, or leave the country for international postings.

## **2.3 Economic Impacts of HIV/AIDS**

HIV/AIDS has two major impacts on organisations, through:

- staff themselves being infected with HIV
- staff being affected by HIV in their extended families and communities.

**Table 5: Estimated cost per CSO of HIV in the past 12 months (US\$)**

Effect of HIV/AIDS	Malawi	Uganda	Tanzania	Total	Rank
Absenteeism (sick leave)	2299	2412	592	5300	(4)
Medical costs, insurance	3838	21,003	1162	26,003	(1)
Productivity, accidents, replication of work	3397	1763	1563	6723	(3)
Overwork (effect on others)	0	593	313	906	
Temporary staff costs/outsourcing/overtime	1943	1039	570	3552	
Morale	0	16,943	520	17,463	(2)
Management time	4335	420	128	4883	(5)
Loss of organisational memory	0	1555	594	2149	
Death benefits/pensions	3506	1025	115	4646	(6)
Funeral costs	729	514	38	1281	
Unpaid loans	0	0	8	8	
Recruitment	173	697	0	870	
Training costs	36	544	0	580	
Total	20,256	48,509	5090		

The impacts of both infected and affected staff are dealt with in the following two sections.

### 2.3.1 Economic Impact of HIV-Infected Staff

AIDS among staff causes both emotional and organisational trauma. Respondents were asked to estimate the costs to their organisation of having staff ill or die from AIDS-related sickness in the past 12 months. Where respondents estimated the loss of time or impact on morale, this was multiplied by the average salary level of the employee to quantify the time cost. The estimates for each CSO were aggregated in each country study to reach the national study averages given in Table 5.

In order of importance, the worst costs of having HIV-infected staff were:

- 1 medical costs, insurance
- 2 morale
- 3 productivity, accidents, repeating work
- 4 absenteeism (sick leave)
- 5 management time
- 6 death cover or benefits/pensions.

**Medical costs:** research respondents estimated that HIV-related medical costs were costing each CSO an average of US\$26,000 per year. As one Director noted: *'A lot more people going for medical treatment from the office than 5 years ago'*. On top of paying staff medical insurance, many CSOs also often pay extra hospital bills that are not covered by insurance. As one Director admitted, *'I fear to quantify the cost. We have just had two people in the hospital for 1 month each'*. This is worse with HIV/AIDS because the spouse and children are often also infected, so medical costs to the CSO are multiplied.

**Morale:** HIV/AIDS among staff has a very detrimental impact on morale, causing 'organisational depression'. One manager related visiting a sick staff member: *'I have never seen anything like him. Almost every year I have lost a brother or sister or cousin, but this was something else. He looked so dreadful that nobody could go back and visit him a second time. It affected our emotions. We are demoralised and disoriented.'* This is often worse in smaller organisations, where relationships are closer. The declining morale affects motivation. One person commented: *'It is so sad when you see colleagues dying. You start blaming the organisation.'* It is harder to accept when the staff member refuses to admit that they are seriously ill. One respondent remembered: *'staff met several times asking – what should we do? The man refuses to go for treatment despite the doctor's report. It touches us deeply.'*

**Productivity, accidents and replication of work:** the case studies illustrate the unforeseen costs of HIV/AIDS on productivity. Other respondents told similar stories. A number of CSOs admitted that having sick staff was leading to delayed reporting and strained relationships with donors. One commented: *'Having sick staff means the whole vehicle slows down and we are not performing well in some areas. Our reports are 3–4 months late as a result. It is affecting our output and hampers the quality of our work.'* Another related that because the chief mechanic was frequently off sick, they had to contract out his work, costing an estimated extra US\$7500 this year and delaying work for long periods while the vehicle was out of service.

**Absenteeism (sick leave):** respondents in the Malawi study estimated that they were losing 2% of their staff time, 4 days per person per year, through staff being off sick with HIV/AIDS-related illnesses. Productivity is exacerbated when sick staff report for work but are unable to function properly: *'some are sleeping at work for the whole day'*. This phenomenon is now so common that it has been named 'present-eeism'. Frequently staff

### Case Study: The Drain on a Water Programme

One manager in a water programme of one of the CSOs studied has seen six of his 14 staff die from AIDS in the past few years. When two senior engineering staff died within a month of each other this year, he lost more than 30 years' priceless experience. He explained: *'They had drilled all over Malawi. They would say: "That part of Balaka, we will need this equipment. It will take this time and cost this amount." That knowledge has now gone.'* Unfortunately, the drilling work in their last 6 months was so poor that the client insisted it be redone at the CSO's expense. This delayed the programme further and cost the CSO an extra US\$9000, none of which was budgeted for.

To keep the programme running, new staff were recruited quickly, but they were not of the same standard as the deceased. They failed to maintain the equipment, which caused serious breakdowns and repair bills amounting to over US\$14,000. Performance has plummeted, donors are exasperated and staff depressed. The manager related: *'My morale went to zero. When everyone was sick I said, "Let's do this, let's do that" and ... nothing happened. I felt very low.'* Yet despite suffering for many years, this organisation is only just beginning to think through how it might respond to HIV/AIDS. It has no HIV workplace policy, and AIDS is rarely discussed openly in the office.

take a few days off here and there, struggling into work, rather than risk termination. They hide their sickness until they are helpless and hospitalised. The extent of staff sickness, the lack of systems, and the fear of legal problems mean that many NGOs *'have not managed sick leave properly. We are not very strict.'* The impact often has a multiplied and knock-on effect on the organisation. One respondent related: *'Sometimes a programme will come to a standstill because a person holding critical information reports ill for a whole month.'*

**Management time:** as most organisations do not have a formalised policy response to HIV/AIDS, when issues arise it is often the leadership who have to deal with them and/or provide cover themselves. Malawian and Tanzanian respondents to the leadership questionnaires estimated that they spent more than 6% of their management time on HIV-related issues. One noted: *'It does eat my time. I am crying for that time. I have to constantly chase people. I have to do things for them. Should I really be draining my energy on this? I end up chasing and chasing.'* Having sick colleagues also costs staff time. Respondents related: *'If we see a colleague showing HIV-related symptoms we talk and spend significant amounts of time sitting and discussing.'* It is an ongoing drain on management time.

**Death cover or benefits/pensions:** CSOs pay significant amounts either in death benefits for deceased staff or, more commonly, paying death cover within pension schemes and life assurance. The costs of this have risen considerably as a result of HIV/AIDS. In Zimbabwe, life assurance premiums have quadrupled over a 2-year period as a result of HIV (Daly 2000). Death cover amounts to 2.5–6% of salary costs in Malawian CSOs.

The other areas of potential cost were not so financially significant in the short term. However, the long-term reduction in organisational capacity through loss of learning and skills should not be underestimated. Five out of 10 Ugandan CSOs indicated that they had lost organisational memory due to HIV. The extent of this cost depends on the level of the staff member who died. While drivers and security guards are easier to replace, those at a more senior level take longer (although the social costs are just as high). To save time and

### Case Study: Childcare Responsibilities

The Director of one of the CSOs in the study describes how HIV in her family affected her work. As a single mother with two grown daughters, she was delighted to be invited to go for a holiday with the eldest, who was living in the UK. She was even sent an air ticket and secured 1 month's holiday. But on arriving in the UK, she was shocked to find her daughter in hospital. It seems she had called her mother to the UK to look after her, without disclosing the actual situation.

As her daughter continued to languish, the mother stayed on. At first the Board was very sympathetic and continued to pay her salary, but after 6 months they felt that, for the sake of the organisation, she must either return or have her contract terminated. At this stage the daughter's health was picking up due to treatment, so she returned home to Uganda – only to find her other daughter now sick. She was obviously unable to take further time off, so she went to work during the day and spent evenings and nights caring for her. This clearly took an immense toll on her emotionally and physically, and had a considerable impact on her productivity at work.

**Table 6: Costs due to staff affected by HIV/AIDS (US\$)**

Effect of HIV/AIDS	Malawi	Uganda	Tanzania	Total	Rank
Absence for funerals	3576	7366	2262	13,204	(2)
Psychological distress – loss of productivity	136	13,266	1834	15,236	(1)
Absence for sick family	1156	993	1450	3599	(4)
Exhaustion from funerals	0	98	0	98	
Management time	866	4596	2184	7646	(3)
Total	5734	26,319	7730		

costs, CSOs appear to be replacing deceased staff with people with lower skills. This may result in a critical decline in performance.

### 2.3.2 Economic Impact of Staff Affected by HIV in their Families

The costs to CSOs of staff affected by HIV in their families may be worse than the costs due to HIV-infected staff. Almost every CSO staff member in these countries has a family member who is HIV+.

Respondents estimated the costs of having family sick or dying from HIV-related illnesses. They recalled how many days they had taken off for attending HIV-related funerals in the past 12 months. This was averaged among staff and multiplied by the salary bill to calculate the financial cost to the CSO (Table 6).

**Psychological distress – productivity:** the most significant cost of working in a context of high HIV prevalence was estimated to be psychological distress. Knowing you have very sick relatives at home cannot help but affect your performance at work. As one respondent described: *'You cannot concentrate. You have to restart the same work over and over again.'* Another mentioned that staff: *'... are really stressed and stretched. I have staff in here in tears about nursing their sick brother at home. She would come to work and ask me – what do I do? My brother is dying.'* Staff morale can suffer when a relative is sick. In one NGO interviewed, *'a staff member's wife was chronically ill with TB. When he realised it was AIDS, he started drinking heavily and came to the office drunk so often that eventually he was sacked.'*

CSO staff salaries are rarely adequate to absorb the extra costs of having sick relatives. They need money for treatment, medicines, hospital bills, food, transportation and communication while the patient is still alive. When the patient dies, the affected staff pay for funerals and care of orphans and widows. This affects productivity – there are frequent requests for advances, and increased use of the CSO's assets, such as vehicles and telephones, for funerals. Some organisations indicated that *'staff became more money-minded than before in their search for money to meet their additional responsibilities.'* This can result in staff doing private work to supplement their income (seven out of 10 Ugandan CSO staff admitted to this), distracting them from work, and sometimes possibly creating even greater temptation for corruption.

**Absence for funerals:** culturally, in all three countries, it is extremely important to attend funerals: *'According to our culture you cannot abandon sick relative. You just cannot say no.'* As a result, in most CSOs time off for funerals, even if limited in the conditions of service, is not strictly enforced, but is a rising cost. In Malawi, respondents estimated that 5% of staff time (more than 11 days per person per year) is lost to funerals. In Tanzania, this figure was estimated at 4 days in the interviews; and 14 days in the confidential questionnaires. As one Tanzanian Director said: *'In my organisation some staff may attend an average of 10 funerals per month. One staff came to me asking permission for 7 days off-duty. This is after attending two funerals. I was obliged to grant her the days requested because as a Director I could see all signs of exhaustion and low morale.'* Accurate records of time off are rarely kept, as permission can rarely be refused. The cost is greater than the actual number of days taken: *'Even if staff come to work after a funeral, they are not productive for at least half of the day and usually request to go home by lunch time.'*

**Management time:** managers also have time diverted to deal with sickness among extended family members, requests for salary advances and arranging for cover when staff are away.

**Absence for sick family:** some female CSO staff were expected to take time off work to care for sick relatives at home – particularly for immediate family. One Director said: *'One of my most experienced field-workers has just asked me to let her work mornings only. Having endured the trauma of watching her three young children die in the last 4 years, her husband is now critically sick in hospital and she needs to look after him. What should I do? Our terms and conditions limit is 5 days' compassionate leave, but he will need her care for much longer than that. But if I give her more, the organisation will suffer and it will set a precedent... '* Even if they do not stop work, the care that women in particular provide can have a knock-on effect on the organisation. One CSO Director in the study had just spent the past 6 weeks sleeping fitfully at the hospital caring for her aunt, who was dying of AIDS. Obviously this compromised her performance at work during the day.

## 2.4 Gender Impacts

Gender clearly has a considerable influence on how HIV/AIDS affects organisations. Across the world, 'The traditional domestic and nurturing roles of women mean that they bear most of the burden of care' (ILO 2003:2). Almost all the stories heard by the study of how CSO staff are affected by HIV in the family, were stories of women.

The 84 leadership questionnaires filled in by 62 respondents (15 female) in Malawi and 22 in Tanzania (seven female) reveal significant gender differentials. This does not mean that men are unaffected (they are expected to contribute financially, in particular) – but they are not affected in such an extreme way as women. Working women are doubly disadvantaged: as employed people they are subject to financial demands; as women they are subject to greater social demands. An employed African woman, regardless of her professional duties, is still expected to perform the cultural roles of care and support.

**Table 7: Gender impact of HIV on CSO leaders\***

Impact of:	Malawi		Tanzania	
	Male	Female	Male	Female
Disposable income spent on HIV-related issues (%)	32	53	12	20
Number of people paying medical costs for HIV/AIDS	2.3	3.5	0.8	3.1
Disposable income spent on medical costs (%)	12	17	1.4	7.5
Number of extra dependents due to HIV/AIDS	2.8	3.9	1.3	2.3
Disposable income spent on dependents (%)	13	30	7.6	9.5
Number of funerals attended per year	14.6	13.2	10.1	10.6
Number of work days per year attending funerals	15.8	12.9	13.3	14.6
Time lost to funerals per year (%)	7	6	5.9	6.5
Disposable income spent on funerals (%)	7	6	2.9	2.8
Management time spent on HIV-related issues (%)	6	8	5.6	7.2

\*Data from Uganda still pending.

From Table 7 we can see that:

- women take responsibility for paying for more HIV-infected family members – in Malawi they take on more than 50% more; in Tanzania more than 400%
- women take on more dependents, such as caring for HIV-orphans, than their male counterparts – 41% more in Malawi; 78% more in Tanzania
- in Malawi, women estimate they are spending 53% of their disposable income on HIV-related issues; in Tanzania, 20% – in both countries women spend about 66% more of their income on HIV than men
- there is no obvious gender differential in terms of time off for funerals – respondents estimated that they take almost 15 days in Malawi and almost 14 days each year in Tanzania.

The interviews and stories above demonstrate that women face extra pressures in terms of taking time off to care for immediate family.

- Women are expected to provide care for the sick, and it is customary for women to sleep the night at the hospital when a patient is admitted. As one male respondent pointed out: *'How many men have you seen in hospitals? They are never there. They hire nurses to care for their patients.'* This is corroborated by a study (ILO 2003), which found that women with a sick husband spent up to 45% less time doing agricultural or other income-earning work than before the illness struck.
- Women face both professional and cultural demands. Women leaders are under extreme psycho-social pressure, which may be exacerbated by their physical proximity to sickness and death. As one respondent said: *'The fact that women are closer to the problem, they are more affected emotionally and physically.'*
- Women spend more management time than their male counterparts on HIV-related issues within the organisation (in Malawi and Tanzania, women leaders spent 33% more time; in Uganda, four times as much time).

The CSOs surveyed were also analysed according to the gender balance in their staff. The most gender-balanced estimated that they lost double the amount of staff and management time than those with the least percentage of female employees. If more gender-balanced

### Case Study: Over-extending Families

Another CSO Director, head of an AIDS NGO, relates how HIV affects her and her family. She is married in her early 30s with one child of her own. But her husband is now sick. Over the past 6 years, three of her sisters and one of her brothers have died, leaving her, as next-of-kin, with 14 orphaned nephews and nieces to look after. Her father is diabetic and very ill in the village, and was being cared for by her elderly mother.

When her mother died recently, she was left alone. She was facing the challenge of leading a growing AIDS home-based care NGO, raising 15 children on her own, caring for her sick husband and looking after her father in the village, 8 hours' drive away. In defiance of her culture and the expectations of her community, she did not take everyone to live in the village with her and her father, but brought them all to her home in the city instead.

CSOs pay higher indirect costs, this means they will appear less efficient than male-dominated CSOs. This might lead to discrimination, with funding being channelled away from those with 'higher overheads'.

## 2.5 Influence of Organisation Type

The estimates from responding CSOs were analysed by a number of additional variables, including:

- size
- age
- faith-based or not
- HIV-focused or not.

**Size of organisation:** smaller CSOs have been harder hit by HIV costs than larger ones. Smaller CSOs have lost a higher proportion of staff – 10% compared with 6.4% in medium-sized CSOs and 7.6% in larger ones. Smaller CSOs have paid 51% higher direct costs and also 55% higher indirect costs. But larger CSOs lose a higher percentage of their staff time. This finding is corroborated by research in the business sector, which found that productivity losses and direct costs of HIV/AIDS are worse in smaller companies, whereas in larger companies staff benefits are the major costs of HIV (Haacker 2004)

**Age of organisation:** only one in eight of the younger CSOs (fewer than 10 years old) had experienced a staff death from AIDS. Consequently, few young CSOs believed that any of their staff were HIV+. For example, of the three young Tanzanian CSOs, all said that not one of their staff was HIV+. Older CSOs were more aware of possible infections among staff. They were also experiencing higher indirect costs (12.5%) than younger CSOs because management was spending more time on HIV issues, as more staff were sick and also perhaps because it was easier to take time off.

**Faith-based organisations:** FBOs experienced exactly the same percentage of HIV-related deaths as non-FBOs. But responding FBOs believed their staff were 33% less HIV-infected than secular responding CSOs. For example, in Tanzania one responding FBO had lost seven staff from AIDS (which researchers knew from other work), but when asked in the interviews all respondents said that no staff had died in the past 5 years. There is still a strong perception in religious circles that, because HIV is associated with promiscuity, *'HIV is a dirty disease that you cannot associate with a clean church.'* The research also revealed that FBOs had 24% lower direct costs, but 36% higher indirect costs. This suggests that, although benefits and salaries in FBOs may be lower, FBOs take their social obligations towards their staff very seriously. Staff and management invest considerable time in providing support to sick staff.

**Organisations with an HIV/AIDS focus:** only four HIV-focused NGOs took part in the study, so the figures are tentative at best. While their direct and indirect costs are the same, HIV-focused CSOs assume their staff are not infected (unless it is an organisation for people living with HIV and AIDS, PLWHA) much more than non-HIV CSOs. They believe the problem is 'out there'. They believed only 3% of their staff might be HIV+, which is significantly less than the local prevalence.

## 3 CSOs' Responses to HIV/AIDS

While many individuals are aware of the costs of HIV, this has not yet translated into awareness and action at the organisation level. In interviews, individuals were able to identify how HIV was affecting their organisation (although this was not an exercise they had done before). But they did tend to underestimate the impact. For example, as Table 2 reveals, CSOs in Malawi and Tanzania are underestimating infections among staff – in Malawi their estimates for staff infections are only a quarter of the local prevalence rate, and in Tanzania only one-tenth. Not one of 120 respondents used urban HIV prevalence to estimate how many of their staff might be HIV+. As one respondent said: *'we have never tried to use statistics to estimate the number of our staff who may be infected.'* Consequently, CSOs are failing to appreciate the full gravity of the situation.

### 3.1 How are CSOs responding to HIV?

CSOs' internal responses to the pandemic have been very limited. One of the most basic and obvious responses to HIV is to develop a policy. Yet of the 29 CSOs in the study, only three had a policy that could be described as being 'implemented'. All the others either had not started at all, or were in the policy-drafting stage. Much of the CSO response to date has come from donor encouragement or even pressure. None of the four AIDS-focused CSOs had an internal HIV policy. One director admitted: *'It is regrettable that we are not doing anything. We cannot cheat ourselves that because we are a faith-based organisation we have no problems in this area.'* Another said that: *'We take it for granted that people know.'*

Much of the internal response that CSOs have made to HIV/AIDS is an 'informal', non-HIV-specific response. CSOs, particularly in Malawi but also in Uganda, provide support through

#### Case Study: Unwritten, Informal Policies

One programme manager told this story, even though it was not known in the organisation.

*'A while back I was increasingly falling sick. I asked myself: "Why am I getting malaria so often?" and so went for an HIV test. I was found HIV+. For the first few months I tried to buy ARVs [anti-retroviral drugs] and nutritious food from my salary, but being married with four school-going children, this quickly overstretched the budget.'*

*'I felt I had to talk with someone. I felt the Director was a sufficiently caring and open-minded person to approach – not to ask for organisational support (as our organisation had no HIV policy), but more to share my burdens and worries. When the Director heard my story, he spoke with a Board member in confidence and gave me an advance. These advances continued, and I am not even sure they have been repaid. The Director also helped me access information about who to talk with, what was happening to my body, and with this knowledge my fears died down. As a result, I have now been able to get onto the Government free-ARV programme. I still do not feel able to share my status openly in the organisation, but sharing it with the Director has made all the difference.'*

general medical schemes and pensions. CSOs in all countries are also responding by allowing staff time off to care for and visit the sick, condoling and attending funerals. This is a social response, and one that is not costed or monitored. Some argue that such a response is culturally appropriate for CSOs in Africa, but others question whether this is not an example of CSO laxity with donor-financed resources. They see this response as diverting programme money and time to deal with HIV-affected staff – with few, if any, questions asked.

In terms of formal responses, the main activities being undertaken by some CSOs include:

- HIV policy development
- welfare committees
- staff awareness training
- staff focal points and HIV counsellors.

**HIV policy development:** an organisational response to HIV is often simplistically equated with HIV policy development. This is a useful first step, but is far from being the complete answer. Yet, even where they do exist, HIV policies are rarely implemented. Most of the initiative for HIV policy had come from donors, and these were treated more as a funding hoop than a strategic priority. As one respondent said: *'We just picked the policy from another organisation.'* Sometimes new staff are not even aware that such policies exist. In one of the three organisations described as 'implementing the policy', only two in four staff interviewed were aware of its existence. Many of these policies are stronger on highlighting organisational commitment than requiring individual commitment. For example in Uganda, only one of the 15 organisations – including INGOs and private sector organisations – required any cost-sharing contribution from individuals. The policies also often focus more on curative/treatment responses to staff and dependents who are already infected than on preventive responses to maintain the health of existing staff. Yet such curative approaches are more costly. There is a lot that can be done regarding prevention without investing considerable resources.

**Welfare committees:** these are an innovative response to HIV that do not go as far as a more formal HIV policy, but do provide important benefits. In one CSO in Uganda with a welfare committee, each staff member contributes US\$3 per month and submits a list of 10 dependents. This committee takes on responsibility for visiting sick staff members (and close family), removing an important burden from overstretched directors. As well as using money from the fund for care and support of family members, people contribute something and buy something themselves for the visits. This appears to be a pragmatic way of cost-sharing, which also builds teamwork.

**Staff awareness and training:** the majority of CSOs identified staff training in HIV awareness as an important response. Many brought in external resource people, particularly PLWHA, to sensitise staff. Often this was linked to the HIV policy-development process. A number of respondents in the different countries asserted that these programmes were one-off inputs and not followed through. They were described as *'ad hoc efforts'*, *'occasional briefings in which the Director says something'*, that in many cases have been discontinued. Other respondents felt their efforts at mainstreaming HIV in their community work had an important impact on staff awareness and development in this field. By training beneficiaries, *'indirectly our staff will be talking to themselves.'*

**Staff focal points and HIV counsellors:** seven out of 10 CSOs in Uganda had appointed HIV focal point persons for others to consult for advice and to identify relevant training and information. This was rarer in Tanzania and Malawi, and in some cases where a focal person had been appointed, they were not replaced when that individual left the organisation. Also, some CSOs had appointed and trained internal HIV/AIDS counsellors, but this did not occur frequently. Most CSOs felt they did not have the resources to employ specialists. Other organisational responses mentioned included: provision of condoms; first-aid kits; informally encouraging staff to go for voluntary counselling and testing; changing travel and allowance policies; and providing investment fund incentives for staff who are open about their status.

Some CSOs were apparently taking a more negative approach to avoid the costs of responding to HIV, such as putting staff on short-term contracts. This risk-management measure means that if staff become sick, the CSO does not have any ongoing obligation. Many CSOs also said they had changed their policy on staff loans because HIV made this too risky a benefit to offer.

There were also some notable omissions in the list of CSO responses to HIV/AIDS, including:

- HIV vulnerability assessment – none of the CSOs surveyed had carried out a critical post assessment
- strategic human resource planning – none had instituted measures to ensure replacement cover for key staff (should they fall sick)
- systems to measure or predict impact, or to manage the implementation of an HIV or critical illness policy
- comprehensive budgeting – budgets tended to include only the extra predicted medical costs from working in an HIV context; HIV is still considered a medical issue and responses are to the health of the individual, not of the organisation
- creative fundraising – few CSOs had approached donors to cover the extra costs of working in an HIV-affected context, believing donors would look on such requests unfavourably and they might even jeopardise the funding relationship
- links with external providers – few had strong links with government agencies or NGOs that could provide important services to staff.

**CSO response by organisation type:** the estimated costs of HIV to CSOs were also compared with the estimated number of sick or deceased staff, as well as the status of the CSO's formal policy response. Clearly, CSOs' responses to HIV were influenced by how they had experienced HIV among staff. This, in turn, affected their direct and indirect costs.

- If an organisation had not experienced sick staff, then not surprisingly it had the lowest extra direct costs due to HIV (US\$173 per person per year). This means that it is also the least likely to have an HIV policy. But if it has no policy, then it pays the highest indirect costs (US\$541 per person per year) in terms of absenteeism and impact on morale, for example. Having no policy takes up more management time and there are no controls on loss of staff time. But these costs are less visible than the direct costs.

- The higher the proportion of deaths in the CSO, the less likely it is to have an HIV policy. Policy discussion becomes too personalised and sensitive when people are dying.
- Those CSOs that were in the process of drafting policy experienced lower indirect costs (by 40%). It appears that even discussions about HIV placed some controls on absenteeism. But the drafting process also served to increase direct costs. This may be because having a staff member fall sick triggered the CSO to start developing a policy, but also because staff benefits are increased in response to discussions of HIV.
- The CSOs with an implemented HIV policy had low direct costs (although not as low as those without a policy), but high indirect costs (although not as high as those without a policy). Those with an implemented policy were least affected by staff deaths.

Analysis of the different types of organisation involved in the research revealed the following.

- The size of CSOs made no difference to whether or not they had a policy.
- Older CSOs were least likely to have an HIV policy, indicating that older organisations may be less flexible in responding.
- Faith-based organisations were not only more in denial of HIV within their organisations, but also were 40% less likely than their secular counterparts to have HIV policy. This may be because they were externalising HIV as an issue 'out there', but not an issue for their own staff. It also may be because they do not feel it appropriate to discuss openly sexual behaviour or condoms.
- HIV-focused CSOs also assumed their staff were not infected and, surprisingly, were much less likely to have an internal HIV policy. Not one of the four CSOs in this small sample had an approved policy.

## **3.2 Why is there a limited response from CSOs?**

The limited CSO response is inconsistent with the scale of the HIV threat. There are a number of factors inhibiting response. Respondents in the three counties identified a number of common constraints operating at interlinked (but distinct) individual, organisational and national levels.

### **3.2.1 Constraints at Individual Level**

The response to HIV is inhibited by denial by individuals. Many people, at all levels of the organisation, even when they have reached the AIDS phase, refuse to admit to themselves that they are sick. One colleague in Malawi switched employment one month before he died of AIDS, despite already being very sick and forgoing his benefits by moving jobs. International NGOs in these three countries have experienced much more limited take-up of *'critical illness fund provisions than is needed by staff. This may be a product of people not accepting themselves that they are sick as well as not wanting it known by others.'* This self-imposed stigma and denial is a reason why HIV testing is such an important first step in a positive response.

Even if individuals admit to themselves they are HIV+ (and only 10% of people know for sure from testing; WHO 2005), they fear the stigma imposed by others. Stigma regarding HIV is still a very powerful social pressure in all three countries. HIV is still largely viewed as a consequence of *'socially unacceptable promiscuous behaviours, with consequences that will render an infected person useless and hence overburdening to others.'* One Malawian Director put it in clear terms: *'when a staff [member] dies of HIV, when we go to the field our partners view the organisation as promiscuous.'* Most respondents noted that the fear of being stigmatised and discriminated against greatly inhibited people from being tested and disclosing their status. As one said: *'You know the problem of Tanzanians is that they don't go for health check-ups, including HIV tests. Even the few who are forced to test, do not disclose. Now, how can an organisation have measures for people who don't disclose?'* As a result of the perceived stigma, CSO staff members do not agitate for a workplace policy in case other staff then suspect them of being HIV+.

Fear of job loss is part of the stigma. Many respondents believe that once they are discovered to be HIV+, they will be terminated as they will be a burden to the organisation (even though they are protected by labour laws). Changes towards shorter-term job contracts feed this fear.

### **3.2.2 Constraints at Organisation Level**

At this level there are constraints regarding:

- putting values into practice
- unsupportive leadership
- organisational culture
- short-term strategies
- weak financial and human resource systems
- structure
- lack of staff competence
- lack of financial resources.

**Putting values into practice:** some respondents asserted that CSOs are not responding to HIV because, at a fundamental level, they do not actually believe in their stated organisational values. Instead, some CSOs are seen as simply a vehicle for generating employment and income. As one CSO leader bluntly admitted: *'Many of us are briefcase NGOs existing only for self interest.'* Such CSOs are not really concerned about looking after their workforce. As one Tanzanian respondent said: *'Most CSOs are not committed to supporting their workers, but just to impress their donors.'* On the other hand, those CSOs that do demonstrate compassion for their staff sometimes find their response to HIV paralysed by the conflicting demand for financial survival. There is sometimes a difficult choice to be made between being seen as a *'caring'* organisation and surviving financially. One Director related a recent management discussion: *'I said, "we would like to be nice, but we are not a charity. If we close then everyone will suffer". My staff said I was cruel.'*

**Unsupportive leadership:** this is a critical factor in determining organisations' responses to HIV. It is clear that some leaders did not have enough knowledge about HIV – according to one male Director: *'Where the head lacks knowledge and skills, and worse still where*

*the organisation is headed by a male who often does not want to admit their ignorance, a response may be difficult.* Some leaders did not push an organisational response because they felt they did not have the individual skills to deal with infected staff. As one commented: *'I felt lost when one person disclosed to me.'* For other leaders, it was their attitude and will that constrained response. Some managers are not receptive to new ideas and do not want to initiate new and costly organisational changes. They are more concerned with simply ensuring short-term financial survival of the CSO, with salaries paid at the end of the month. A number of respondents also pointed out that some CSO leaders' lifestyles are perceived as 'reckless' and therefore they believed a good proportion of CSO leaders are likely to be HIV+ themselves. As a result, these leaders may not push their organisation to respond to HIV, *'because they fear if they do, they will be exposed themselves.'*

**Organisational culture:** closely related to values and leadership, an organisation's culture can inhibit the response to HIV in a number of ways. As one respondent put it: *'With our current culture we cannot respond in any way (to the threat of HIV/AIDS internally)! I have a feeling if a staff [member] falls ill they will just get rid of him and employ another one.'* The organisation's culture may promote denial (as illustrated by some FBOs). If stigma exists in the organisation's culture, if it is gender-insensitive or has a hierarchical power culture – all these inhibit an effective and appropriate response. Some of the organisations interviewed appeared 'depressed'. In the face of HIV at home and at work, respondents were overwhelmed by a sense of powerlessness and had lost hope that anything positive could be done. There was a resignation and acceptance of HIV/AIDS. As one person said: *'We take it as a normal part of life. If someone is sick we just say "Ah, this is normal".'* Or as another put it: *'Sometimes we just don't like to think and preoccupy ourselves with something as negative as HIV/AIDS.'*

**Short-term strategy:** CSOs are failing to analyse the external environment and determine whether, and by how much, HIV affects them. Instead, their response to HIV depends on whether a staff member has fallen sick; or they are driven by project funding opportunities and deadlines. Internal response to HIV is a long-term issue that is seen to distract staff and management from short-term project deadlines. CSOs find it difficult to set aside time to reflect and learn from the changing environment, especially in relation to their vulnerability to HIV/AIDS and its impact. CSOs' focus is also on making a difference 'out there' in the lives of communities, not spending time on themselves. As one respondent stated: *'We do not realise that HIV will negatively affect us. We think of it in terms of our programmes and beneficiaries – after all, the NGO sector is about service to others.'* It is also exacerbated by pride: *'We think we are better off than those we are teaching'* – there is a stigma about the problem being close to home. Where CSOs have responded, this has often been driven by donors rather than by internal strategy. Many CSOs interviewed echoed that: *'If Cordaid had not put HIV onto our agenda we might not have done anything yet.'*

**Weak finance and human resource systems:** this means CSOs are often unaware of the organisational costs of HIV, which are hidden in programme budget lines. Respondents also said their lack of knowledge of the actual costs of HIV/AIDS had severely inhibited proactive responses. As one respondent lamented: *'We are only now in the draft stages of the policy, but we have suffered for many years. We agree we have suffered, but nobody has taken the time to say how much this has affected us. Because no economic value has been attached, it has been neglected.'* Many CSOs also do not have the complementary systems in human

resource management, finance, and monitoring and evaluation systems to enable them to respond adequately. CSOs are also not able to budget for a response. As one stated: *'We have a fear of the unknown – if we go this way, shall we find the money to cover this? We do not want to promise the moon in developing a policy, which we cannot then deliver.'*

**Lack of staff competence:** respondents cited a lack of skills or confidence in the human resource departments to deal with HIV/AIDS: *'Our focal person does not have the competence. They fear their lack of knowledge will be exposed.'* Another four CSOs in Uganda admitted to low levels of awareness about HIV. They expressed a *'lack of access to accurate information and resources. We are ignorant, but research such as this one triggers deeper reflection on the impact on overall institutional performance.'* There is also a perception that developing a workplace response is such a complex, sensitive and potentially costly area that it requires contracting-in considerable expertise in order to respond at all.

Lack of financial resources: budgets are funded by donors and tied to projects. CSOs still perceive most donors as unwilling to support the internal costs of responding to HIV (seen as driving up overheads). They pointed to *'a donor limit on administration expenses/salaries. They are only interested in activities and numbers of beneficiaries.'* Donors were perceived to be more interested in *'trimming CSO budgets'* than supporting extra HIV-related costs. Consequently, CSOs believed that *'everything HIV-related had to be done within the 5–10% administration ceiling'*, or by paying for it with other sources of income. CSOs do not think donors want to contribute to supporting a workplace policy – only HIV programme work. Organisations worry about costs that may never have an end, and it is never clear how long support will be needed – *'where does this money come from?'* so they ask: *'Is it sustainable?'* In different ways, every organisation believed that responding to HIV was expensive, yet many responses to HIV do not cost money. As the International Labour Organization puts it: *'If you lose someone you have trained for 20 years, that is a great loss. Condoms and AIDS education costs peanuts'* (ILO 2002). But assumptions about donors had not really been tested, as many CSOs had not even dared to approach them. Certainly, many INGOs do match the preconceptions of African CSOs, but Dutch NGO donors such as Cordaid, the Humanist Institute for Development Co-operation (Hivos), the Interchurch Organisation for Development Co-operation (ICCO), Oxfam Novib and STOP AIDS NOW! are extremely positive in their encouragement of workplace responses (Holden 2006).

### **3.2.3 Constraints at National Level**

At this level there are cultural, religious and political constraints. Cultural attitudes to HIV are intertwined with individual fears of stigma and job loss. National experiences such as the public sector retrenchment in Tanzania, when health status was used as a criterion for employment, have left a legacy of national fear that sickness will lead to termination.

In societies where religion plays a powerful role, responses to HIV are constrained. In faith-based societies, HIV is still thought of as *'resulting from "ungodly" behaviour, so we do not want to talk about it.'* HIV/AIDS is perceived as a sign of infidelity, and many churches do not wish to be thought of as encouraging promiscuity through promoting condoms.

*'The existing National HIV/AIDS Policy cannot be of any use if it is not translated into a law,'* according to one respondent. The Tanzanian HIV/AIDS National Policy was written 5

years ago, but remains a political statement without legal framework for enforcement. The absence of a law requiring employers to respond to HIV/AIDS (by making workplaces safe and secure) gives employers room to avoid fulfilling their social/corporate responsibility.

### 3.3 Insights from International NGOs and the Private Sector

The private sector has led the response to HIV/AIDS in the workplace. Many of the large multinational companies, such as Heineken, Volkswagen and Anglo American, were the first to predict the impact of HIV on their profits, and consequently initiated comprehensive workplace responses. In the NGO sector, international organisations such as Oxfam, ActionAid, Novib and Cordaid have all invested considerable time and resources in working out how to address HIV within their organisation. To help local CSOs learn how other organisations in their country are responding, this research project analysed the experiences of three commercial firms and two INGOs in each country. This gives CSOs a benchmark for what is possible.

Although the private sector is generally viewed as having responded appropriately, most firms in these countries have not responded. In Uganda, only 11% of workforces have an HIV policy (Fleming 2004). It was difficult for the researchers to identify examples of good practice, especially among smaller local firms. This mirrors a survey of 1000 South African companies in 2004, which found that only about 25% of companies had implemented a formal workplace policy (Bureau for Economic Research 2004.) This declined to 13% for companies of fewer than 100 staff. According to Bendell (2003:24): 'The private sector is systematically shifting the burden of HIV/AIDS onto other stakeholders through discriminatory practices, reducing benefits and out-sourcing low skilled jobs.'

Yet it is clear that some firms and INGOs are taking the threat of HIV seriously, and have developed comprehensive responses to mitigate the impact. Some of the elements of good practice that local CSOs can learn from are highlighted below.

#### 3.3.1 Examples of Good Practice

**Vulnerability assessment:** the best of the companies and INGOs have all undertaken risk assessments to determine their vulnerability and susceptibility to HIV/AIDS. This pinpoints key specialised workers, the loss of whom would lead to a bottleneck. These groups are targeted with HIV/AIDS risk-reduction programmes.

**Preventive measures:** prevention is a critical element of the best responses to HIV. All had been involved in training and awareness programmes for staff, and also for spouses: '*These awareness-raising events include the spouses of staff members to encourage openness, not only among staff but also with their spouses. The spouses are also made aware of what is covered under the policy.*' They often use outside facilitators (PLWA or Red Cross). They had also provided information through information, education and counselling materials; involvement in the Red Ribbon Campaign; and the use of intranets. Some firms take this education element so seriously that managers have to pass HIV/AIDS competency tests. They all provide easy access to condoms, and some put first-aid kits in vehicles in case of accidents.

Policy development: all the good practice exemplars have an implemented workplace policy. They found that a participatory design process involving staff (and trades unions) improved ownership and quality of the policy. These policies were often based on guiding principles linked to the organisation's stated values. In many cases these policies were not restricted to HIV, but covered other critical illnesses.

**HIV/AIDS testing:** companies and INGOs encouraged staff to go for voluntary counselling and testing, by paying for tests and in some cases offering incentives. Some of the larger firms had the resources to do the counselling and testing in-house, but most linked with government and NGO services in this field. They placed a strong emphasis on confidentiality.

**Care for those infected:** good practice organisations offered support to infected staff through providing access to treatment (often by paying for services from external suppliers). Such expenses were covered largely by medical insurances, but some INGOs had also set up 'catastrophic illness funds'. Anti-retroviral drugs were usually covered. Most companies and INGOs paid 100% of the medical costs, although some asked staff to pay a nominal 5–10%. Cover was often extended to the spouse plus up to four dependents. In some cases, INGOs provided nutrition packs for infected staff and families. As well as financial support, good practice organisations provided psychosocial support through trained counsellors – usually in-house, but also externally. They also had staff designated as HIV focal points to coordinate and maintain the organisational response.

### 3.3.2 Learning Points from INGOs and the Private Sector

The response to HIV is influenced more by the international/local variable than by the private sector/NGO variable. Most local firms have done as little as local CSOs in responding to HIV/AIDS. International companies and INGOs are more conversant with HIV. Many can employ specialists who have the time, opportunity and responsibility for HIV. Also, they are often a critical distance from the reality on the ground. The local reality may be too sad, too personal, and too depressing for those living within it. International organisations are also more aware of international standards and national labour laws. Their size means there is often money available internally for what is deemed a strategic priority.

It is difficult to achieve a balance, with the organisation taking responsibility for addressing this issue without removing individual responsibility. International NGOs, in particular, may find their generosity is taken advantage of.

INGOs and private sector organisations have found monitoring of the HIV workplace response extremely difficult. The necessity to maintain confidentiality at all costs makes it difficult to track and tag expenditure on HIV, opening it up to abuse.

Despite the high-quality response from many INGOs, disclosure among staff is still very low. Only about 1–2% of staff are taking advantage of the services and incentives offered, preferring to avoid the stigma of being seen as HIV+. It is often only when they are hospitalised that they take advantage of policy provisions.

A policy response on its own is not sufficient, as issues such as cultures of fear and stigma in the organisation inhibit action. By giving responsibility for managing the organisational

response to human resource departments, many private sector firms and INGOs inadvertently send a message that HIV is only a human resources issue.

There was a striking dissonance among the INGOs surveyed between their internal response and their support for partners' responses. They do not apply the same values to partners as they do to themselves. Asked whether they would be willing to give same support to their partners as they offer to their staff, one said: *'it would be costly and ambitious to expect that kind of support for partners' policies. We would support the development of a policy but not the implementation of the policy because our priority is the poor. We promote partner independence and encourage partners to share the principles of coping with HIV/AIDS.'* Another INGO said it would take a lot of consultation with their head office, but it might be able to fund seed grants. Neither INGO would provide ongoing partner support. Some even go as far as ensuring they go to a different hospital from the local NGO partner, saying: *'We are the donor and cannot sit in the same waiting room as our partners.'* What underlying values do these responses bring to the surface?

## 4 Ways Forward

The ILO predicts that in the next 5 years a further 536,500 Malawians, 362,200 Ugandans and 757,600 Tanzanians will die from AIDS-related sicknesses (ILO, 2004a). Table 8 indicates how the current impact of HIV/AIDS is likely to change over the next 5 years.

With these predicted increases, a CSO in Malawi with 60 staff would have one staff member die every year of AIDS and two develop symptoms of full-blown AIDS. Given that the ILO figures are based on national statistics, urban-based CSOs may be more even more starkly affected. Greater availability of ARVs may mitigate these costs to some extent. Yet even if ARVs were available to 100% of those who need them, they will not cure the problem, but will only slow down the impact. So how should CSOs, INGOs and donors respond to this worsening situation? In the following sections we explore possible ways forward.

### 4.1 How Should CSOs Respond?

CSOs do not appear to be sufficiently aware of the current economic costs of AIDS to their organisations, let alone factoring into their plans that it may get worse. There are many difficult questions, and certainly no easy answers – but ways forward for CSOs do exist. Inaction will lead to higher costs. According to Barnett and Whiteside (2000:31): 'The total cost can be significantly reduced if the decision to act is pre-emptive rather than delayed until after the emergence of a serious problem.'

In an increasingly competitive funding context, there will be a process of natural selection over the next decade, with 'the survival of the fittest'. If CSOs do not develop resilience to HIV/AIDS, they will die out. A pre-emptive organisational response should show an understanding of the environment; leadership thinking and acting strategically; appreciation of the value of human resources; care for staff; and a determination to address potential organisational weaknesses. Respondents highlighted a number of valuable actions CSOs can take to mitigate the impact and build their resilience to HIV, including the following.

- Take an organisational development approach to HIV. Any workplace response to HIV needs leadership, trust and openness if it is to work.
- Start with the leadership – their behaviour, openness and commitment have a major influence on the organisation's response. Issues of power and gender also need to be integrated.

**Table 8: HIV/AIDS projections for 2005–10**

Country	Estimated HIV-related deaths 2000–05	Predicted HIV-related deaths 2005–10	Predicted loss in working population 2005–10 (%)	Predicted change in 5 years (%)
Malawi	450,500	536,500	8.3	19
Uganda	443,800	362,200	2.5	-18
Tanzania	713,700	757,600	3.6	6

Source: ILO (2004a).

- Consider the organisation's values and culture. An effective response to HIV requires a culture of openness and responsibility, rather than stigma and discrimination.
- Understand the impact of HIV on the organisation. An impact assessment/risk analysis, however informal, is needed to help people recognise the urgency of the situation and the costs of doing nothing.
- Consciously link the strategies for mainstreaming HIV externally in programmes, and internally among staff.
- Take a strategic approach to human resources, ensuring key posts are covered by other staff (through shadowing or multi-skilling interventions).
- Build on informal systems, and be appropriate for the stage of the organisation's development – a less formal policy may be adequate and better placed to promote appropriate action. These systems should value and build on existing informal networks and support structures (such as welfare committees).
- Develop responsibility at all levels – organisational response and donor support alone is not the answer; there is also a need for individuals to take personal responsibility.
- Link responses to HIV not just to an HIV policy, but to strengthening the whole organisation.
- Ensure HIV policy development but also implementation – this needs to be monitored and documented to ensure CSOs adapt as their context changes.
- Develop systems for capturing individual learning for the organisation, so that if a staff member gets sick, the impact on the organisation is mitigated.
- Monitor and track expenditure such as that on medical expenses and absenteeism.
- Train staff in HIV awareness as well as counselling, including spouses where possible, and using first-hand experiences of PLWHAs.
- Link with existing support services and develop links with others for more resource-intensive treatment and care programmes. There may be potential for creating a database of providers able to offer HIV support, and for working with other CSOs to negotiate favourable terms and confidential systems with health insurance companies.
- Learn actively from others' experiences in this field.
- Budget realistically based on current impact and future risk assessment. Donors should be approached to cover part of the costs, but individuals should also contribute. STOP AIDS NOW! is developing a tool to assist partners to budget realistically on a cost-sharing basis.

## **4.2 How Should Capacity-building Providers Respond?**

HIV/AIDS changes the types of capacity-building services needed by CSOs in sub-Saharan Africa. This has implications for how providers themselves should operate. Currently, even if there was appropriate demand for assistance with mainstreaming HIV in organisations, there is a dearth of supply of such services. This bottleneck could prove critical if capacity-building providers do not respond. Some of the ways capacity-building providers can respond are listed below.

- Stand back, reflect on and analyse how working in a context of high HIV levels might affect their work. They need to understand better the impact of HIV on their clients and their services, so that they can adapt in order to remain relevant.

- Start small – although it is certainly a complex area, there is much that capacity-building providers can do without considerable technical expertise in HIV. What is needed is simply to create a space to ask the right questions. How are we experiencing HIV? What impact might it have on us and our organisation? How can our organisation respond in a way that encourages the organisation’s survival and also meets individual needs?
- Build on their skills in analysing organisations, and their own daily experiences of living with HIV in both families and organisations. Helping CSOs to respond may be more about confidence than competence.
- Assist CSOs to undertake simple impact and risk assessments in order to understand the organisation’s situation and context. The response can then be tailor-made for their individual context.
- Take an organisational development approach to assist the mainstreaming of HIV, for example by highlighting organisational values and culture, and looking at issues of leadership, power, gender and organisational learning.
- Focus on CSO leaders initially, to persuade them to push the agenda from the top. This may involve short awareness sessions highlighting the threat of HIV to their organisation, and follow-through in the form of coaching and mentoring leaders on how they can respond. Assisting an organisation to respond to HIV will require personalising the issues – organisations only change when people change. So, for example, it may be useful to start with the personal impact of HIV on staff, then go on to explore the organisational impact.
- If asked to assist a CSO in organisational development, capacity-building providers should take an HIV-sensitive approach. HIV issues should be integrated with other organisational processes such as strategic planning. Capacity-building providers need to take every opportunity to ‘sow seeds of awareness’. This needs to be done during contract negotiation, not just during implementation and reporting. In this way, the client will not feel that HIV has hijacked what was intended to be a different process.
- Offer appropriate HIV policy development based on the phase of the organisation’s life – for example, for a young, founder-led CSO it may be more effective to ensure the commitment of the leader than to develop a formal policy document.
- Mainstream HIV in their own organisation for reasons of integrity – to practice what they preach. This also develops first-hand experience of some of the challenges and issues, and confidence to help others.
- Develop competence and confidence in HIV mainstreaming. Capacity builders need to access information about this field and exchange learning. This can be done through research, documentation and dissemination of lessons, and exchanges to share good practices of training, methods and impact.
- Advocate that donors respond appropriately to HIV in partner CSOs. HIV capacity building is a long-term process, not a one-off workshop or policy. Long-term financing is needed to support this ongoing process.

### **4.3 How Should International NGOs and Donors Respond?**

The research revealed that in a context of high prevalence of HIV, any CSO will pay more money for less output. There is an inherent organisational cost to working in such a

demanding environment. The question is: who pays? Some INGOs, particularly Oxfam and those in the Dutch STOP AIDS NOW! Coalition (Cordaid, ICCO, Oxfam Novib and Hivos), have not only put these issues on partners' agendas, but have also shown solidarity by providing support to partners in ground-breaking ways (Holden 2006). They have risen to the challenge of becoming more than 'concerned bystanders' (Kerkhoven and Löwik 2004).

The INGOs interviewed for this research, however, were very reluctant to support the costs relating to HIV, offering at best only one-off seed money. As these INGOs were implementing and paying for comprehensive responses to HIV for their own staff, it appears that very different principles and values apply to partners. Their behaviour is still dictated by a 'project' mentality. For many, this may be because they simply do not know about the costs, and have not considered how they can support partners effectively. So how can donors who genuinely would like to implement their policies of partnership respond appropriately? How can they encourage partners to respond proactively to the epidemic without removing ownership and responsibility? CSO respondents made a number of suggestions.

- Some said that developing a workplace response should be a donor condition. They felt that the situation is so urgent and serious that donors need to exercise their financial power – *'by the time we wake up, we will be dead.'* Others said that a response to HIV must not become a condition, as this would remove ownership and encourage second-hand HIV policy documents that are never implemented. They said: *'Let us die a bit and take responsibility ourselves.'* Any response should be part of a dialogue on broader partnership issues, and part of the appraisal, monitoring and evaluation processes.
- Donors do have an important role in funding CSOs' responses to HIV/AIDS, and should not expect this to be covered as 'administration' expenses. Some INGOs, such as Cordaid, have requested a specific HIV-response budget line and indicated their willingness to provide funding. Respondents felt that donors should not just focus on beneficiaries, but *'should help implementing organisations with sorting out their internal HIV/AIDS-related challenges.'* Respondents wanted donors to: *'Listen to us and understand the impact on us. Be ready to support these elements of sickness and funerals in budget lines.'* They should also fund staff awareness programmes; the costs of implementing well developed HIV/AIDS policies; and materials such as condoms, travel kits and information, education and counselling materials. These extra costs mean more investment, perhaps in fewer partners, and for donors to *'take a long-term perspective'* on partnerships.
- Donors need to fund research, workshops, publications and dissemination of good practice organisational responses to HIV/AIDS. CSO respondents in Malawi felt that they needed practical case studies of how others have responded, and what they are doing. They felt that *'nobody has shared this with us yet.'*
- Donors need to develop clear, open guidelines for support to partners, including the amounts acceptable for implementing a response to HIV/AIDS in the workplace (including extra medical bills, funeral costs and temporary cover) (STOP AIDS NOW! 2006).
- Donors could also stimulate partners to respond by making them more aware of the organisational costs of HIV/AIDS through dialogue, field visits and dissemination of information.

- Donors could sponsor projects that seek to enhance understanding around the multiple dimensions of HIV/AIDS, through partner workshops and workplace response consultancies.
- At a wider level, donors may need to work together to develop the supply and quality of local providers of capacity-building services in HIV/AIDS mainstreaming.

## 5 Conclusions

The main aims of the research were to test the hypotheses that:

- HIV/AIDS is placing significant economic costs on CSOs
- CSOs have yet to implement an effective response.

The research highlights that HIV/AIDS is already placing significant financial and social costs on CSOs. This corroborates the findings of the pilot study (James and Katundu 2006). Working in contexts of high HIV levels is costing CSOs considerably more money for considerably less output and performance. These costs are likely to underestimate the true impact of HIV/AIDS, as they rarely take into account the costs of declining morale, overwork and stress, loss of organisational memory, etc. The impact on CSOs is worse than the impact on the private sector. This may be because of their small size, and even greater denial among CSOs who are '*meant to know and meant to behave morally.*' The impact has a gender face – women are more affected than men by expectations of their performing a caring role. The costs also weigh heavily on CSO leadership (a very scarce and mobile resource). Leaders are paying very high emotional and financial costs in looking after their family members and staff. The strategic implications of such figures need very careful consideration, as for some CSOs their very survival is at stake.

Yet the national prevalence of HIV in Malawi (14.2%), Uganda (7%) and Tanzania (8.8%) is far lower than some other countries. Botswana (37.3%), Lesotho (28.9), Namibia (21.3%), South Africa (21.5%), Swaziland (38.8%), Zambia (16.5%) and Zimbabwe (24.6%) have been much harder hit. The organisational impact on CSOs in these countries urgently needs to be analysed in order to catalyse a proactive response.

The research revealed that although individuals can identify the costs of HIV, they are underestimating the current infections among staff in Tanzania and Malawi. In all three countries studied, the organisational implications and future costs are not recognised.

Consequently, responses of CSOs to this threat are at best limited and *ad hoc*. The impact of the epidemic on CSOs in the countries studied far outpaces the action. The response is even less in faith-based organisations. To be experiencing an annual reduction in development impact of at least 10% (perhaps closer to 15%), and to do be doing very little about it, is a major failure of leadership. To argue that responding to HIV/AIDS is not urgent enough is simply no longer tenable. Waiting until the crisis comes – when a valued staff member becomes sick – makes developing an organisational response even more difficult, as any organisational policy discussions will be interpreted personally.

A considered response is essential. Declining aid budgets for CSOs mean there will be fall-out, and survival of the fittest. Responsiveness to HIV in the workplace may be the best single indicator of CSO capacity. While CSOs need to take responsibility for responding appropriately, INGOs and donors cannot remain comfortably on the sidelines as their partners struggle with the disease. They must become actively involved in assisting their partners to respond in a strategic and cost-effective way if they are to remain relevant in sub-Saharan Africa.

HIV/AIDS presents us with a unique opportunity and challenge. It is exposing pre-existing inconsistencies and anomalies in the aid system, and in the management of CSOs. The only

way to build organisational resilience to the disease is to implement the good management practices (such as empowering, gender-sensitive decision-making) and good donor practices (such as partnership) that have remained development rhetoric in the past. For many CSOs, their very survival demands that this rhetoric finally becomes a reality.

## References and Bibliography

- Aantjes, C. (2005) *Taking the Initiative: HIV/AIDS in the Workplace in Ethiopia, Africa* Amsterdam: STOP AIDS NOW!
- AVERT (2006) The Impact of HIV and AIDS on Africa. [www.avert.org/aidsimpact.htm](http://www.avert.org/aidsimpact.htm)
- Barnett, T. and Whiteside A. (2002) *AIDS in the Twenty-First Century*. Basingstoke, UK: Palgrave Macmillan.
- Bendell, J. (2003) *Waking up to Risk: Corporate Responses to HIV/AIDS in the Workplace*. UNRISD Paper No. 12. Geneva: United Nations Research Institute for Social Development.
- Bureau for Economic Research (2004) *The Impact of HIV/AIDS on Business in South Africa*. Stellenbosch, South Africa: University of Stellenbosch.
- Connelly, P. (2005) *The Impact of HIV/AIDS on NGOs/CBOs in South Africa*. Lesotho: CARE South Africa. [www.caresa-lesotho.org.za/Admin/ReadNewsLetterContentFrame.asp?Id=289&SubId=67](http://www.caresa-lesotho.org.za/Admin/ReadNewsLetterContentFrame.asp?Id=289&SubId=67)
- Daly, K. (2000) *The Business Response to HIV/AIDS: Impact and Lessons Learnt*. Geneva/London: UNAIDS/Prince of Wales Business Leaders Forum and Global Business Council on HIV and AIDS.
- Fleming, Y. (2004) 'State of Affairs on HIV/AIDS Workplace Policies', Background paper for STOP AIDS NOW! Secretariat. Amsterdam: STOP AIDS NOW!
- Fox, M., Rosen, S., MacLeod, W., Wasunna, M., Bii, M. and Foglia, G. (2004) The impact of HIV/AIDS on labour productivity in Kenya, *Tropical Medicine and International Health*, 9(3): 318–324.
- Garbus, L. (2003) *HIV/AIDS in Malawi*. San Francisco, CA, USA: AIDS Policy Research Centre, University of California.
- GTZ (2004) HIV/AIDS Workplace Policies and Programmes for the Public and the Private Sector, International Symposium, Dar es Salaam, Tanzania, 26–28 May 2004. Eschborn, Germany: Deutsche Gesellschaft für Technische Zusammenarbeit. <https://www.gtz.de/de/dokumente/en-wpp-symposium-report-2004-05.pdf>.
- Haacker, M. (Ed.) (2004) *The Macro Economics of HIV/AIDS*. Washington, DC, USA: International Monetary Fund.
- Holden, S. (2003) *AIDS on the Agenda – Adapting Development and Humanitarian Programmes to Meet the Challenge of HIV/AIDS*. Oxford, UK: Oxfam GB in association with ActionAid and Save the Children UK.
- Holden, S. (2006) *Good Donorship in a time of AIDS: Guidelines on Support to Partners to Manage HIV and AIDS in the Workplace to be used in pilot projects in Uganda and India*. Amsterdam: STOP AIDS NOW!
- ILO (2002) *Action Against AIDS in the Workplace*. Geneva: International Labour Organization.
- ILO (2004a) *HIV/AIDS and Work: Global Estimates, Impact And Response*. ILO Programme on HIV/AIDS and the World of Work. Geneva: International Labour Organization. [www.ilo.org/public/english/protection/trav/aids/publ/global\\_est/index.htm](http://www.ilo.org/public/english/protection/trav/aids/publ/global_est/index.htm)
- ILO (2004b) Women, HIV/AIDS and the World of Work. Briefing Paper. Geneva: International Labour Organization. [www.ilo.org/public/english/protection/trav/aids/wd04en.pdf](http://www.ilo.org/public/english/protection/trav/aids/wd04en.pdf)
- ISS/MIM (2003) *HIV/AIDS and Attrition: Assessing the Impact on the Safety, Security and Access to Justice Sector in Malawi and Developing Appropriate Mitigation Strategies*. Institute for Security Studies and Malawi institute of Management. Lilongwe: Malawi Safety, Security and Access to Justice (Program), MASSAJ. [www.sarpn.org.za/documents/d0000619/index.php](http://www.sarpn.org.za/documents/d0000619/index.php)
- James, R. (2005) *Building Organisational Resilience to HIV/AIDS: Implications for Capacity Building*. Praxis Paper 4. Oxford: INTRAC. [www.intrac.org/pages/PraxisPaper4.html](http://www.intrac.org/pages/PraxisPaper4.html)
- James, R. and Katundu, B. (2006) *Counting the Organisational Cost of HIV/AIDS to Civil Society Organisations. Pilot Research Study, Malawi*. Praxis Paper 11. Oxford: INTRAC. [www.intrac.org/pages/PraxisPaper11.html](http://www.intrac.org/pages/PraxisPaper11.html)
- James, R. and Mullins, D. (2004) Supporting NGO partners affected by HIV/AIDS. *Development in Practice*, 14(4): 574–585.

- Kerkhoven, R. and Löwik, M. (2004) 'Human Resource Management and HIV/AIDS', Study among ShareNet members, The Netherlands.
- Lisk, F. (2002) *The Labour Market and Employment Implications of HIV*. Geneva: International Labour Organization.
- Manning, R. (2002) *The Impact of HIV/AIDS on Civil Society: Assessing and Mitigating Impacts: Tools and Models for NGOs and CBOs*. Natal, South Africa: Health and HIV/AIDS Research Division (HEARD), University of Natal.
- Malawi Ministry of Health and Population (2003) *HIV Sentinel Surveillance*. Lilongwe: Malawi Ministry of Health and Population.
- O'Grady, M. (2004) *Managing HIV/AIDS in the Workplace: Examples of Nine NGOs in South Africa, Zambia and Zimbabwe*. The Hague: Oxfam Novib/Oxfam International.
- Rosen, S., Simon, J.L., Thea, D.M. and Vincent, J.R. (2000) Care and treatment to extend the working lives of HIV-positive employees. *South African Journal of Science*, 96(6): 300–334.
- Rosen, S., Simon, J., Vincent, J.R., MacLeod, W., Fox, M. and Thea, D.M. (2003) AIDS is your business. *Harvard Business Review*, 2: 80–87.
- Rosen, S., Vincent, J.R., MacLeod, W., Fox, M., Thea, D.M. and Simon, J.L. (2004) *The Cost of HIV/AIDS to Businesses in Southern Africa*. Boston, MA, USA: Center for International Health and Development, Boston University School of Public Health.
- Sephiri, T. (2002) *HIV/AIDS and Workers' Rights: Understanding the Issues*. Oslo: Norwegian Church Aid. <http://english.nca.no/filemanager/download/269/Nesten%20hele%20Workers%20rights.pdf>
- STOP AIDS NOW! (2006) *Supporting Partners in a Time of AIDS: Guidelines on Good Donorship and Managing HIV/AIDS in the Workplace*. Amsterdam: STOP AIDS NOW!
- TACAIDS, NBS and ORC Macro (2005) *Tanzania HIV/AIDS Indicator Survey 2003–04*. Calverton, MD, USA: Tanzania Commission for AIDS, National Bureau of Statistics and ORC Macro. <http://tanzania.usaid.gov/documents/HIVAIDSIndicatorSurvey20032004.pdf>
- Uganda AIDS Control Programme (2006) Survey Report. Kampala: Uganda AIDS Control Programme.
- UNAIDS, UNICEF, WHO (2005a) *Malawi: UNAIDS/WHO Epidemiological Fact Sheet on HIV/AIDS and Sexually Transmitted Infections – 2004 Update*. Geneva: UNAIDS. [http://data.unaids.org/Publications/Fact-Sheets01/malawi\\_EN.pdf](http://data.unaids.org/Publications/Fact-Sheets01/malawi_EN.pdf)
- UNAIDS, UNICEF, WHO (2005b) *United Republic of Tanzania: UNAIDS/WHO Epidemiological Fact Sheet on HIV/AIDS and Sexually Transmitted Infections – 2004 Update*. Geneva: UNAIDS. [http://data.unaids.org/Publications/Fact-Sheets01/tanzania\\_EN.pdf](http://data.unaids.org/Publications/Fact-Sheets01/tanzania_EN.pdf)
- UNAIDS, UNICEF, WHO (2005c) *Uganda: UNAIDS/WHO Epidemiological Fact Sheet on HIV/AIDS and Sexually Transmitted Infections – 2004 Update*. Geneva: UNAIDS. [http://data.unaids.org/Publications/Fact-Sheets01/Uganda\\_EN.pdf](http://data.unaids.org/Publications/Fact-Sheets01/Uganda_EN.pdf)
- UNAIDS/WHO (2005) *AIDS Epidemic Update: Special Report on HIV Prevention*. Geneva: Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO). [www.unaids.org/epi/2005/doc/EPIupdate2005\\_pdf\\_en/epi-update2005\\_en.pdf](http://www.unaids.org/epi/2005/doc/EPIupdate2005_pdf_en/epi-update2005_en.pdf)
- UN Department of Economic and Social Affairs (2004) *The Impact of AIDS*. New York. [www.un.org/esa/population/publications/AIDSimpact/AIDSWebAnnounce.htm](http://www.un.org/esa/population/publications/AIDSimpact/AIDSWebAnnounce.htm)
- UNDP (2005) *Human Development Report*. New York: United Nations Development Programme. <http://hdr.undp.org/reports/global/2005/>
- UNDP/MIM (2002) *The Impact of HIV/AIDS on Human Resources in the Malawi Public Sector*. Lilongwe: Government of Malawi.
- VSO (2005) *Capacity Building in Times of HIV and AIDS*. London: Voluntary Service Overseas.
- WHO (2005) *Malawi: Summary Country Profile for HIV/AIDS Treatment Scale-Up*. Geneva: World Health Organization. [www.who.int/hiv/HIVCP\\_MWI.pdf](http://www.who.int/hiv/HIVCP_MWI.pdf)

## Appendix 1 Research Methodology

Some of the methodological challenges faced in conducting this research are listed below.

- Identifying the costs of HIV-related sickness and death, and separating these from other illnesses (especially given the problem of social stigma – HIV is still largely a taboo subject and confidentiality is necessary). It is still extremely rare in Malawi, Uganda or Tanzania for HIV+ people to disclose their status, although today most people are sufficiently knowledgeable about the disease and its symptoms to make a reasonable judgement as to whether or not someone has AIDS. This paper therefore uses the term HIV/AIDS as short-hand for 'suspected HIV/AIDS', while acknowledging that, without testing, this remains anecdotal.
- As Malawi, Uganda and Tanzania all suffer from a generalised epidemic, it was not possible to identify a control group of NGOs with no staff affected by HIV. Even in rural areas, there can still be considerable prevalence. Furthermore the 'NGOs' in these areas are highly informal groups with no paid staff, which would make comparisons inappropriate.
- Nor was it feasible, given the resources and ethical constraints of this study, to insist that all staff in the NGOs sampled be tested for HIV, which might have allowed for a control group of the HIV– within each NGO.
- NGOs in Malawi, Uganda and Tanzania do not have monitoring systems to measure absenteeism, so the research relied largely on informants' memories of absences in the past 6–12 months, and deaths in the organisation over the past 5 years. This means the data are more descriptive than scientific, with educated estimates in place of definitive answers. Although recall was the main method, this was triangulated among the four respondents in each organisation to ensure estimates were relatively accurate.
- Organisational incentives to cover up the actual costs – NGOs wish to present a successful face to demanding donors, to create the impression that they have minimal overheads and are performing well.
- HIV/AIDS is a very personal issue, as it involves talking about sexual behaviour and death. At times this meant that interviewees did not want to think about HIV, let alone talk about it. Some faith-based organisations were particularly closed. Confidentiality was often used as an excuse for denial. At times, HIV raised wider organisational fears; one respondent became angry, saying: *'If I fell ill today I would be kicked off and they would simply bring in someone new.'* At other times, researchers were taken aback by the openness of respondents as they related very private, painful and personal stories.
- Respondents found the process of trying to quantify the impact of HIV difficult because most had never thought about organisational costs before. The prevailing culture was not to translate time into economic terms. As one respondent asked, *'How can you put a time on compassionate leave?'* All respondents found it difficult to quantify the cost of diminished morale, exhaustion, and distraction at work.

### Selection Criteria

Ten NGOs in Malawi and Uganda, and nine in Tanzania, were selected to take part in the study. Because of the methodological challenges of asking respondents to be open about HIV, one

**Table A1: Diversity of NGOs in the study**

Country	Size			Age (years)			Faith-based or secular		HIV-focused		Female leadership	
	Small	Med.	Large	≤10	10–20	20+	FBO	Secular	Yes	No	Yes	No
Malawi	2	4	4	3	6	1	4	6	2	8	4	6
Uganda	3	4	3	1	5	4	3	7	2	8	3	7
Tanzania	3	6	0	3	5	1	1	8	0	9	3	6
Total	8	14	7	7	16	6	8	21	4	25	10	19

important criterion for selection was that the researchers had pre-established relationships of trust with the NGOs through previous work. This was based on the assumption that NGO staff were more likely to give more open and accurate answers about HIV to people they knew than they would to strangers. It needs to be recognised that this prior contact might also mean that respondents told the researchers what they thought they wanted to hear. NGOs were selected on the basis diversity in size, age, type and leadership, to ensure they were as representative as possible, from a small sample, of NGOs in the country.

The NGOs were from one urban location (two in Tanzania), with known prevalence of HIV/AIDS, to ensure ease of comparison between NGOs. This also enabled good access and reduced costs of data gathering. Each had been in existence for more than 5 years

## Data Collection

The researchers in the different countries used the same semi-structured questionnaire to interview four members of staff from each NGO ( $n = 112$ ), always including the Director, the Finance Manager, and the person responsible for human resources.

The questions explored the extent of the organisational impact of having staff infected with HIV and affected by HIV in their families and communities. In follow-up questions, interviewees were asked to quantify the HIV-specific financial or time costs. For example, if a member of staff had been off sick with a suspected HIV-related illness in the past 6 months or year, then the number of weeks lost was estimated. Recall was therefore the primary data-gathering method used. These estimations were triangulated between respondents and an average of the four answers was used.

Where there was a significant difference in estimated costs, researchers followed up with the finance manager to obtain the most accurate estimate. The figures therefore need to be used with caution, but do provide important and informed quantitative perceptions in a field where very little data exists.

Secondary data (such as financial reports, time sheets, HIV policies, terms and conditions of service) were reviewed to validate the extent of the extra HIV-related costs, as well as to see how NGOs are responding to HIV/AIDS within the organisation.

A leadership impact-monitoring questionnaire was completed by 62 respondents in Malawi and 22 in Tanzania (in Uganda this will be done as part of the dissemination stage). This quantified the personal impact on leaders in their extended families over the past 6

months. There was a mix of male and female leaders in order to track gender differentials. Although, from a sociological angle, the impact of HIV may be greater on lower cadres of staff, this research focused on leaders because of their more critical role in organisational performance.

Semi-structured interviews also took place with three INGOs and two private sector companies in each of the three countries. This was for comparative purposes – to find out what was possible and good practice in each context.

## Data Analysis

The quantitative interview data were analysed using EXCEL spreadsheets. The findings from the interviews were compared with the leadership impact questionnaires to triangulate the data.

Clearly, not all medical or funeral costs are related to HIV. People get sick and die from other causes. In the absence of full knowledge of everyone's HIV status, a proxy indicator was used – that of percentage of hospital bed occupancy by HIV/AIDS-related conditions in the cities where the research was undertaken. In Malawi and Uganda, 70% of in-patients are HIV+; in Tanzania it is currently 50% (UNDP/MIM 2002; Garbus 2003; ISS/MIM 2003; TACAIDS, NBS and ORC Macro 2005; Uganda AIDS Control Programme 2006). In calculating the economic costs to the NGO, 70% of the overall medical, funeral and insurance costs were estimated to be attributable to HIV/AIDS in Malawi and Uganda, and 50% in Tanzania. The robustness of this assumption is enhanced by the literature. For example, UNDP/MIM (2002:14) states that: 'In countries with an adult prevalence rate of just below 10% almost 80% of all deaths among young adults between 25–45 years are associated with HIV. The proportion of HIV/AIDS related deaths is likely to be even higher in areas with higher HIV prevalence rates.'

Furthermore, interviewees were asked to recall the number of staff deaths in the past 5 years and to estimate how many were HIV-related and how many were not. In Malawi 94%, in Uganda 87% and in Tanzania 75% of NGO staff deaths were estimated to be HIV-related (see Table 2).

## Methodological Benefits

The research process proved to be a valuable capacity-building process in itself. It created the space for people to stop and think about an issue they felt was *'too frightening to contemplate'*. The exercise not only prompted people to check their own lives, but has also already encouraged some to respond in their organisations. One respondent telephoned the researcher to say how useful the interview had been for her, and how she had used her reflections on the questions to alter her budget for the coming year. Another Director mentioned that, at a senior management meeting after the interviews, *'I talked about HIV/AIDS for some time. We discussed what to do with sick staff. My programme manager discussed hiring staff to cover those who were sick.'* Yet another said: *'There are two things that have really made a difference in my working life over the last 10 years and this interview was one of them. I never thought about this before.'* Almost every respondent gave more time to the interview process than they had originally allotted as they saw its relevance.

# The Organisational Impacts of HIV/AIDS on CSOs in Africa

## *Regional Research Study: Uganda, Malawi, Tanzania*

By Rick James with Brenda Katundu, Betsy Mboizi, Emily Drani, Daudi Kwebwa and Rogers Cidosa

HIV/AIDS is having a silent but significant impact on the organisational capacity of civil society organisations (CSOs) in sub-Saharan Africa. To date, we have had no information as to how serious a problem HIV/AIDS is for CSOs.

A three-country research study was designed to address this knowledge gap through a collaborative effort by INTRAC; the Capacity Building Unit for NGOs (CABUNGO), Malawi; the Community Development Resource Network (CDRN), Uganda; and the Organisational Development Training and Facilitation Centre (TRACE), Tanzania. This research assessed the economic and social costs of HIV/AIDS infection for the organisational capacities of selected CSOs in Malawi, Tanzania and Uganda. While the quantitative figures are based on respondents' own estimates, and therefore should be treated with some care, HIV is clearly affecting CSOs in these three countries:

- 62% of the CSOs had experienced at least one staff death in the past 5 years
- 72% of CSOs suspected that one or more of their current staff were HIV+
- Yet CSOs were considerably underestimating the extent of staff infections.

Such a considerable organisational impact, and such a limited CSO response, raise critical strategic issues for CSOs. The future prediction for many countries in sub-Saharan Africa is that the impact of HIV/AIDS will become worse. The survival of CSOs is at stake. Yet HIV/AIDS provides an opportunity. It is exposing many of the inconsistencies and anomalies in both CSOs themselves, and the aid system as a whole. This paper explores these issues and provides recommendations for a strategic response to this problem confronting CSOs today.

ISBN 13: 978-1-905240-08-1

ISBN 10: 1-905240-08-2



Postal address: PO Box 563, Oxford OX2 6RZ, UK

Registered and visiting address: Oxbridge Court, Old Fruiterers Yard, Osney Mead, Oxford OX2 0ES, UK

Tel: +44 (0)1865 201851 Fax: +44 (0)1865 201852

Email: [info@intrac.org](mailto:info@intrac.org) Website: <http://www.intrac.org>

INTRAC is a company limited by guarantee No. 2663769

Registered in England A Registered Charity

Charity No. 1016676