

**Project Empower**

**Strengthening the response to HIV and AIDS**

**Building HIV *positive* Organisations  
“Lived Realities”**

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## 1. Introduction

The blame for the growing and potentially debilitating crisis of HIV and AIDS within civil society organisations is, to some extent, directly attributable to the drive to corporatise the development sector in South Africa. Within a sector that prides itself on its humanness, we have seen an increasing call to systematize and depersonalize development work. The emergence of the logframe and the adoption of corporate models of appraisal, planning, monitoring and management have led to a situation where people in the sector doubt their own ability to relate to each other outside of rigid process and procedure. The sector is losing its human touch. It is quite ironic that the methods, values and principles that have been usurped by the "CSO as a business" model are the very ones that potentially would have provided us with some protection against the emergence of HIV in our organisations.

This paper describes the experience of ordinary CSOs going about their work in communities in KwaZulu Natal and in the Eastern Cape province of South Africa. These experiences have been, and are still being, relayed through Project Empower's programmes<sup>1</sup> in these regions. These experiences are by no means scientific in their method of collection - they are merely the stories of people in organisations with whom we have been able share time and work with.

The paper is divided into three broad sections: a contextual overview of the problems organisations are facing currently; descriptions of how organisations have viewed the development of policy; and some examples of good practice derived from these experiences.

The anecdotes in the paper are drawn from a series of interviews and discussions held with organisations participating in a programme to support the design and implementation of HIV workplace policies in civil society organisations. Some of the views and opinions expressed may not be welcome reflections on the practice within the sector. They are however true, in that they represent the perceptions of people who engage with the system on a day-to-day basis through their work, and as recipients of development services.

## 2. Contextual overview of the problems organisations are facing currently

### 2.1. Description of CSOs

Project Empower has worked over the past four years with over fifty smaller NGOs in KwaZulu Natal and the Eastern Cape. Our purpose in this work has been to draw the attention of leadership to the potential impact of HIV on their staff and to look at ways of mitigating this impact. Many of the organisations we have worked with have been small community based initiatives, providing human rights support, advice and training at a local level. They have perhaps employed between three and six people, who have a depth of knowledge about their own communities, little formal education above a school leaving certificate, but a lot of short course

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<sup>1</sup> Building HIV positive Organisations: working with leaders and staff of organisations to examine, and develop contextual responses to the impact of HIV on the staff of CSOs

informal "capacity building" training run by other NGOs. The formal staff complement is supplement by a pool of volunteers who come and go. Most organisations receive a bare level of funding with little commitment from the donor beyond at best the next year. They pay pathetically little as a salary, sometimes below accepted urban minimum wages for unskilled workers, and provide no benefits such as medical aid and pensions or provident benefits. Despite the lack of formal benefits, the organisations have been encouraged by the "capacity builders" to put rigorous and often rigid human resource and other management measures in place which function within a strict hierarchy of authority.

## 2.2. Struggling to survive

The experience of many organisations is of struggling to survive. A commonly shared experience has been the endless battle to find and secure resources to ensure the continuation (not sustainability) of the organisation and its programmes.

Some of the consequences of this have been that:

- staff and volunteers receive low salaries and stipends
- very few organisations can provide benefits for staff and volunteers
- employees in CSOs have no job security

This has in turn resulted in high staff turnover as employees often see CSO workplaces as stepping stone to better things: taking the time to learn as much as they can, to embellish their CVs and to find better paying, more secure jobs.

Coupled with this already grim situation, the emergence of HIV and AIDS and the impact these have on human and financial resources in the CSO workplace has pushed many organisations to the brink of collapse.

HIV and AIDS compound the loss of skilled and experienced staff and as a result organisations are staffed by people with little or no experience, without sufficient time to learn and develop because of the demands to deliver on their programmes.

## 2.3. Responding to HIV – whose agenda?

Organisations are under a lot of pressure to respond to HIV and AIDS. Communities are in desperate need of HIV and AIDS related services and pressure organisations that they see as credible to provide them. "The community has always looked to us. In the face of HIV, we can do nothing to help. We feel desperate and useless as staff" says one land reform leader.

The decision to respond or not respond to community needs is a difficult one when viewed in the often contradictory obligations of their values (of being pro-community) and remaining true to their core purpose. These decisions that have to be taken place immense emotional burdens on staff and are major drivers of stress in the workplace. In one workshop run last year by Project Empower, participants named HIV as a primary stressor

of staff in their organisations, not because their staff members were living with HIV themselves, although they may have been, but because every day staff witnessed the devastation caused by HIV in the communities – sickness, death, poverty, orphans – felt dreadfully pressured to respond and yet finally unable to do anything with any longer term value. In the words of another leader: "HIV is killing the soul of our community"

In addition to the pressures placed on organisations by communities, donor pressure also plays a significant role in driving up the organizational stress levels. HIV and AIDS have become the major thematic area for many donors and CSOs feel driven towards starting HIV and AIDS programmes to meet donor expectations – and to access funding. CSOs confront sustainability issues on a daily basis and feel compelled, often without questioning, to follow the trends donors set in order to ensure that organisations are able to survive and provide communities and their staff with some stability.

For example, many community based organisations, run and staffed by men, address gender based violence as a primary issue. Addressing gender relations has been clearly placed on the agendas of organisations by donors. On discussion with some of the staff members, a feeling of deep resentment often emerges from the male staff members towards their female clients and towards the women in their lives as they believe that men's issues are overlooked in favour of women's.

Donor pressure to keep up with current trends has also created a situation where organisations lose significant amount of time and capacity to training programmes. The immediate relevance and application of the stuff of these training programmes is not obvious and sometimes, beyond a short verbal or written report, the newly trained staff person simply picks up where they left off.

Large amounts of energy and resources are dedicated to making organisations policy compliant even though they lack the resource and internal capacity to enable policy. Examples of this are gender and HIV mainstreaming policies that have become little more than documents that can be displayed in support of fundraising. At times, they are cynically developed for this express purpose.

#### 2.4. Forgotten people skills

In a recent workshop, we unpacked the potential impacts that HIV, unaddressed, could have on NGOs. High on the list was unhappy relationships between staff members in the workplace. Commented one leader: "I think this is already happening. People are very unhappy and there is a lot of gossiping and back biting in my organisation. I do not think it is because of HIV, but I do not know what to do about it."

Interpersonal relationships within many organisations are fraught with tensions with complaints that range from race to dissatisfaction with remuneration. At the heart of many of these tensions are the unhealthy power relationships that exist within CSOs. Many organisations are

autocratic and hierarchical. Management practice is poor and relationships between staff is strained. In the context of HIV and AIDS, because of the deep emotional content of HIV, these become all the more evident and, in some cases, threaten to seriously damage the organisation.

There is often a dissonance between the public face of the organisation and the practiced values and principles that is especially evident in interpersonal relationships of staff. For example, an organisation, running a home based care programmes, forbids staff members to consult doctors or attend clinics during work hours, and forces them to take leave for this purpose. This organisation, by the way, does not offer the staff members concerned a medical aid.

Staff of CSOs feel ill-equipped and afraid to deal with emotions in the workplace and, when confronted with the emotions that accompany HIV and AIDS, are incapacitated. In addition, the drive to professionalise NGOs had led leaders to believe that any indulgence of emotion in the workplace is inappropriate and a symptom of poor leadership. Because HIV has come to be seen as an area in which only professionals can practice, ordinary staff members often do not trust that they would "say the right thing" when confronted with a grieving colleague, and the general silence caused by the fear of conversing about HIV in the workplace compounds the problem of stigma.

#### 2.5. Accessing appropriate services

Organisations, even when they do sometimes have sufficient resources to make benefits available to staff are confronted with questions of quality of support service delivery. Private service delivery is hugely expensive compared to the paucity of money available to NGOs. There is a huge divide between rural and urban settings in the availability and quality of services. It is also often the case that services are inaccessible because of their medium of delivery (written and spoken English) and the distances people have to travel to get to them.

While antiretroviral treatment (ARV) is available in the public sector. Treatment and testing sites are limited and there is a high demand to access programmes. The quality and availability of treatment varies significantly from facility to facility. In some cases it has been reported that health workers are not trusted and that they do not respect confidentiality.

The situation in small, local CSOs in South Africa is dire. They face both a financial and human resource crisis at a time when HIV and AIDS are having a significant impact on their ability to manage work and deliver on their programme objectives. All of this at a time when poor State infrastructure and contesting ideologies around treatment, care and healthy living makes it impossible for many people to access good quality services in the public sector.

CSOs have, though, seen the need to do something to respond to HIV in their midst. Their responses may seem minimal to many, but they are contextual and take into account a myriad of local attitudes, values, practices and practical constraints that are often ignored by the people who define the sectoral response.

In the following section we look at some organisations' responses and highlight the particular challenges that they present for the development sector as a whole.

### **3. HIV policy development Descriptions of the responses of individual organisations**

Policy responses to the impact of HIV and AIDS have varied widely. The nature of these responses has largely been determined by:

- donor policy requirements for funding
- the limits of organisational resources – financial and HIV expertise
- organisational culture
- a crisis within the organisation (illness or death of a staff members)

#### **3.1. Human relationships in the workplace**

A determining factor in the response to HIV has been the culture of the organisation. Discussion around the issues of HIV has highlighted skewed power relations within organisations that are not always evident to outsiders. Responding to HIV under these conditions is impossible. Organisations have to make adjustments to their practice in so that they can deal with HIV and AIDS effectively.

#### **3.2. Reasons for not developing a policy**

While most organisations are conscious of the need to develop a workplace policy, - it is something you "should have" - many have not attempted to begin the process for different reasons.

For some, it seems to be a slight on their staff. Aware of the stigma surrounding HIV, developing a policy seems to some to be an outright accusation. Some leaders speak of staff members "alleged" HIV status, as if, though criminal, it has still not been proven and hence should not be discussed. Others are simply afraid of initiating discussion around such a loaded and emotional subject for fear of disrupting and unmanageable consequences.

For others, there is a very real acknowledge that for the policy to be meaningful it has to make provision for some services to be offered to infected and affected people. When it is difficult to deliver these services or continue their delivery in the longer term, then it is better not to offer them in the first place. Resourcing medical costs (ARVs and the treatment of opportunistic infections), additional staff, education and awareness programmes, etc are generally not available to most organisations who already have small operational budgets and lack the confidence to negotiate improved funding arrangements with donors.

### 3.3. **The value of policy in a resource poor environment**

Other organisations, more pragmatically acknowledge that provision of services is beyond their reach, but do use the development of policy to engage staff in dialogue around HIV and to create a more enabling people environment for disclosure and interpersonal support

### 3.4. **Policy development processes**

Policy development in some organisations has not been participatory. Managers, sometimes with the assistance of consultants, have drafted and instituted policy without staff participation. In most cases policies drafted in this way are not implementable: disclosure is unlikely to happen in this context.

When organisations have embarked on a participatory or consultative policy development process, it has opened up space within the organisation for colleagues to discuss HIV: to develop knowledge, interpersonal skills and emotional comfort around the issue. Even if the policy eventually does not make provision for treatment, the open space can be very helpful.

### 3.5. **Internal and external mainstreaming**

Organisations, responding to pressure from the communities and the donor community, have also embarked on processes to mainstream HIV into their work. What this has largely involved is the establishment of home-based care projects, education and awareness campaigns (distributing literature) and programmes targeting orphans and vulnerable children (OVCs). This is often done without sufficient internal expertise and diverts organisational resources away from their core work. In many cases though these organisations believe they have no choice but to respond because they are often the only service provider in that area or they 'need to do HIV work' to get funds.

While most organisations have in some way adjusted their programmes to incorporate HIV, this awareness has often not come back home to their own organisations.

## 4. **Examples of Good Practice**

Some examples of good practice derived from these experiences  
The organisation discussed here is not based in a local community but operates out of a smaller city in KwaZulu Natal. It is driven by a strong social activist Christian agenda, and in our experience, has been one organisation that has successfully grappled with the experience of living with HIV. To some extent, this has been because it has been better resourced, and has been able to provide a basic medical aid for staff, which has helped staff to take better care of their health. But this alone would have been meaningless, as there are many examples of HIV positive people dying with access to medical support that they have never used.

These are some of the steps taken by the organisation which we believe have made a difference:

- 4.1. understanding experience of people living with HIV in different contexts and use the analysis of this experience as the basis for gathering more information and knowledge. This approach helps us all to become more expert on the issues of HIV,
- 4.2. learning in this way from the experience of people living with HIV gave impetus and content to both what is commonly called internal and external mainstreaming. It found that the needs of HIV positive community members and HIV colleagues were not fundamentally different
- 4.3. learning in this way – highlighting experience - encouraged and allowed staff members living with HIV to disclose their experiences to their colleagues. Instead of PLWHA being a "problem" in the organisation about whom solutions needed to be sought, positive staff members became a key resource and the "experts" on the issue and thus became the leaders as the organisation sought to understand how it should respond to HIV. This is a very positive experience of GIPA, and an example of allowing people living with HIV within organisations to assume leadership organically rather than searching for HIV activists from outside.
- 4.4. the organisation recognized its porous boundaries: it attempted to learn from and address the experiences of community members, volunteers and staff, instead of treating these as separate and different entities.
- 4.5. HIV policy development was inclusive, consultative and led by a team of staff members, not the director or a consultant. The process enabled wide ranging discussions within the organisation, revealing difficulties, areas of disagreement and conflict, rather than hiding them, and allowing the organisation to be aware and to address them
- 4.6. policy development has gone through many stages of development, is frequently reviewed, is currently under review, and its implementation monitored by an implementation committee. This process recognizes that experience is fluid, that issues change as the epidemic develops, and that policy is not an end on itself.
- 4.7. the implementation committee co ordinates both internal and external mainstreaming. The two are not seen as separate processes, competing for attention and resources, but are integral to one another.