



Praxis Note No. 50

# The means is the end: Reflections on the process of developing HIV workplace policies

by Rachel Smith and Project Empower

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**INTRAC**  
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## **The means is the end?**

“It’s too much effort. If our donor really insists on us having an HIV policy, let’s just download one or adapt someone else’s. We haven’t got time to waste on such distractions to our real work.”

How often have we heard or even had this response ourselves? We are tempted to short-cut the process. But if we do, this may do more harm than good. Instead we need to take the policy development process seriously, as this Praxis Note from Project Empower explains. They learnt from a recent workplace programme with thirteen NGOs in KwaZulu Natal, that the process of policy development was more important than the final product. The ‘means’ was actually the ‘end’.

In this paper, Laura Washington and Mpume Mbatha – Project Empower staff and facilitators – share how they facilitated highly participatory and meaningful workshops around HIV and AIDS in the workplace. This unique approach has yielded sustainable and positive results in developing workplace responses to HIV and AIDS. They reflect on this approach and highlight practical ways to create the positive environment necessary for an effective workplace response to HIV and AIDS.

## **A ‘magic bullet’ for addressing HIV and AIDS in the workplace**

Some donors require evidence of an HIV workplace policy as part of the funding assessment process. Others see the policy as critical in managing the impact of HIV and AIDS in the workplace, particularly for NGOs working in high HIV prevalence areas. Whatever the reason, HIV workplace policies are increasingly seen to be essential internal documents for NGOs working in developing countries. For many, the means or process of developing the policy is often irrelevant. Any policy, arrived at by any means, is seen as better than no policy.

Organisations often throw a policy together using a quick internet search and the application of a generic template. There is little staff participation. When employees are asked to comment it is usually to rubber stamp a policy which means very little to them. So what is the purpose of the policy? Why are HIV workplace policies important and how should we be thinking about, and writing them?

## **Living in denial**

HIV and AIDS remain difficult topics to discuss, despite many years of information dissemination and awareness campaigns. Stigma and discrimination are widespread in many workplaces. And though many organisations have been quick to respond to HIV and AIDS in the community, as the Director of one NGO says, “we hadn’t translated them from outside activities to internal responses”. The devastating daily reality of HIV and AIDS in the community and in employees’ personal lives has made it ever more difficult to address HIV and

AIDS in the workplace. Many organisations live in a state of denial.<sup>i</sup>

Yet, whether we want to think about it or not, we cannot dispute the importance of a sound workplace response to HIV and AIDS. It enables an organisation to effectively cope with the impact of HIV and AIDS on staff and their families. It ensures a productive and supportive environment, and ultimately ensures the organisation's survival. A positive response creates a positive organisation.

## Building HIV-positive organisations

“Only after we had lost a staff member to AIDS did we realise what the organisation could have done, and what it could do in the future.”  
Director of a local NGO in KwaZulu Natal

Prior to working with the thirteen organisations in KwaZulu Natal and Limpopo, Project Empower had already thought a great deal about what it means to be an ‘HIV-positive organisation’ and how that might look in different parts of the workplace. They found that organisations responding positively to HIV and AIDS in the workplace typically:

- Sought to understand the experiences of people living with HIV and AIDS in different contexts. They used this analysis as the basis for gathering more information and knowledge – helping everyone within the organisation to become more informed on issues of HIV and AIDS
- Recognised the porous boundaries of the organisation and sought to learn from and address the experiences of HIV-positive community members, volunteers and staff instead of seeing these as separate and external
- Did not see people living with HIV and AIDS as a ‘problem’ to solve, but saw HIV-positive staff as ‘experts’ on the issues and encouraged them to be leaders on the organisation's response to HIV and AIDS
- Developed an HIV workplace policy through an inclusive, consultative and team-led process. This enabled discussion, acknowledged conflict

and areas of difficulty (instead of hiding these) and addressed these issues

- Frequently reviewed and amended the HIV workplace policy (as issues changed the epidemic developed). They monitored its implementation through a committee of staff members
- Led the response through HIV focal point persons and staff committees that would coordinate both external and internal mainstreaming.<sup>ii</sup>

In the early stages of the policy development process Project Empower assessed the workplace responses of the thirteen organisations. The assessments were based on the concept of ‘HIV-positive organisations’. Semi-structured interviews and discussions with staff and management looked at the existing response to HIV and AIDS and what they would like to see happening. Following this, Project Empower began a process of intensive and in-depth workshops with the staff, management, volunteers and board members of the different organisations.

The following sections look in detail at Project Empower's process and the methods they used to facilitate the development of effective HIV workplace policies.

## Project Empower's process – the means

With all that we know about good practice in development work, Project Empower's approach to HIV workplace policy development should not be quite so unique. We know that participation is important for meaningful and sustainable change. We know that power relationships are important, particularly when talking about HIV and AIDS. And we know that a ‘one size fits all’ approach rarely works whatever the intervention.

Yet Project Empower's focus on personalising the impersonal – making collective workplace responses relevant to the individual employee – is different. It

yields positive sustainable changes within organisations. The end is not the written policy. The end is really the change in organisational and individual behaviour that have been brought about through the process of developing the policy.

## **Personalising the impersonal – ‘Lived realities’**

“Honouring people’s stories is phenomenally important because these are the realities of people’s lives”.

Mpume, Project Empower

When we talk about workplace responses to HIV and AIDS we must start right at the beginning. All workplace policies, HIV or otherwise, deal with people. People are complex. We each have our own way of looking at the world, shaped by our experiences, our feelings and emotions, our prejudices and our beliefs. To ignore this is to ignore the very things that make us exciting, dynamic beings engaged with the people and world around us.

Project Empower put individual people right at the heart of all its work. Project Empower facilitators help participants to explore their ‘lived realities’ – the everyday life experiences and power relationships that influence and control their behaviour. As a workshop participant recalls:

“sharing stories about ourselves was very valuable. We understood more about each other than before. We had been making assumptions about people and why they behaved the way they did. Hearing their stories was like a light coming on. It has helped to build a family and feeling of togetherness within the workplace which has remained.”

NGOs develop contextually applicable strategies by sharing experiences of HIV and AIDS and understanding people’s behaviour in the workplace. This results in the creation of a supportive working environment. There is space for discussion, allowing stigma and discrimination to be addressed and removed from the workplace.

## **‘The Journey’**

“The process is story driven – it has to be because when it’s close to people’s realities, it is ingrained in what people know and how they respond.”

At the start of Project Empower’s workshops, participants are asked to consider their individual experiences of HIV and AIDS – their ‘Journey’ and to plot these on a timeline. This process is guided by questions such as:

- When did you first encounter HIV and AIDS?
- What happened?
- Where were you?
- How did you feel?
- What happened next?

This is a powerful tool that enables participants to personalise the issue of HIV and AIDS. It highlights that all the organisation’s employees have been, and often still are, affected by HIV and AIDS. Participants open up about HIV and AIDS and how it has affected them. It prepares the ground for discussing how to address HIV and AIDS in the workplace.

Fostering an open, supportive and understanding environment is crucial. An employee needs to feel accepted in disclosing their HIV status. They know that they will be supported by their employer and fellow colleagues to live and work positively.

## **Physical and emotional ‘burnout’**

Whilst being an incredibly valuable and essential part of the process, Laura and Mpume stress that facilitating ‘The Journey’ must come with a warning. The workshops are often the first time that people have had the opportunity to talk openly about their experiences of HIV and AIDS and all that this entails.

Laura remembers a particularly poignant workshop: “One participant had buried fifteen members of his family in two years. It was the first time he had let it out and talked about it”. Facilitators must be able to deal

with the emotions that arise when people are talking about their experiences of HIV and AIDS. Sensitive facilitation of these situations is crucial. In some countries it is a requirement to have a trained counsellor present to counsel participants.

There is also a real danger of staff burnout for those facilitating these sessions. Laura and Mpume both experienced physical and emotional exhaustion at certain points during the project. They warn that facilitators can get too caught up in people's emotions and carry a heavy burden of pain and sorrow. On the other hand, they can become immune to people's stories of suffering. Neither of these responses is emotionally healthy or conducive to productivity at work. As Laura and Mpume learnt, "measures, such as additional leave entitlements, sabbaticals, staff counselling and debriefing sessions must be built in to the process".

## Using imagination to address difficult questions

Workplace policy is sensitive. When it comes to negotiations between staff and management, the battles lines are drawn and everyone is prepared for a fight. Employees expect that their needs will not be addressed, let alone their voices heard and listened to. As one workshop participant remembers: "We expected management to develop the HIV policy, we didn't expect to be able to speak openly." Experience also tells employees that policies can have a detrimental and regimental effect: "Policies belonged to the boss... people heard about policies if they had done something wrong. They were used in a correctional sense." On the other hand, management fear employees will make demands that cannot be implemented due to resource constraints.

It is easy to forget that management teams are made up of people, and those people are not immune to HIV and AIDS. They have also suffered the effects of HIV and AIDS on their families and friends and some might also be HIV-positive themselves. They know that there needs to be a workplace response, yet they are restricted by limited funds and limited know-how.

Project Empower's approach to developing HIV workplace policies enables policy issues to arise organically and to be addressed in contextually appropriate ways. The workshops encourage participants to think from a personal perspective rather than brainstorming hypothetical policy issues and ideas. By asking questions that require participants to imagine themselves as an HIV-positive employee and then later as a manager, organisations are able to flush out the issues and benefits that would matter most to employees. The discussions help to reduce stigma and discrimination and address misconceptions and myths. The result is stronger relationships between staff, volunteers and managers at all levels of the organisation. We now look at some of the key questions that Project Empower use.

### 1. If you were living with HIV what would you like the organisation to do for you?

"I would want to be treated the same".

This statement was repeated over and over again in the different workshops. In the same way that they would not want to be stigmatised, employees felt that, if they were HIV-positive, they would not want to be fussed over, pitied and treated in a special or different way. Bending over backwards to address the perceived needs of HIV-positive staff can breed resentment for both the individual concerned as well as their colleagues. This is not to say that good will and humanity do not go a long way. They do. But treating HIV-positive staff differently to other staff does not always have the intended results.

Management often expect employees to produce a long list of expensive benefits, medical aid schemes and other costly responses. However, what employees really wanted was a dignified set of support services that wouldn't disrupt their identity of themselves as independent autonomous beings. Simple responses would have the biggest impact; respect for confidentiality, creating a non-discriminatory work environment and support to enable employees to attend clinic appointments.

Asking employees to consider what they would like the organisation to do for them if they were HIV-positive can be one of the most important questions in the process. It highlights simple inexpensive workplace responses which can make a big difference to HIV-positive employees. This drives management commitment to the process and builds a collective and cohesive response from both managers and employees.

## **2. If you were living with HIV, what would you be able to contribute to the organisation?**

When we think about workplace policies we often have two thoughts; disciplinary procedures from managers, and entitlements for employees. We often turn first to the page in the staff manual that deals with time off, annual leave and medical cover. We can sometimes focus on our benefits with little thought to our responsibilities and how we contribute to the organisation. But we do contribute. Either because we want to ensure our pay cheque at the end of the month, or because we passionately believe in the work we are doing. Often both. But how does this fit into an HIV workplace policy? And what can we expect of an HIV-positive employee?

There is a danger that HIV-positive employees are seen as sickly and no longer able to contribute to the work of the organisation. Yet we know that a person living with HIV can live a healthy normal life and work for many years. Where anti-retroviral treatment is available and accessible this is even more the case.

Mpume and Laura reflect, "in response to this question workshop participants across the different organisations would say things like 'I would be able to contribute the same work as before the diagnosis' and 'I would want to stay well so that I can continue to contribute to the organisation'". Such responses reinforce the message that HIV-positive employees would continue to have roles and responsibilities that they fulfil regardless of their HIV status. This starts to create the positive work environment which becomes woven into the fabric of the HIV workplace policy.

As well as thinking about the situation from an HIV-positive employee, it is vital to look at the

issue from the organisation or management perspective.

## **3. If you were the organisation's management, what would you expect from an HIV-positive employee?**

By standing in the shoes of management, employees started to see the bigger picture. They were concerned not only with their own welfare but also the welfare of the organisation. They recognised the responsibility of the organisation to the community.

Consequently, staff became increasingly concerned about the organisation's ability to function effectively. Participants started to shift their thinking away from individual needs and wants towards the collective needs of the organisation. Participants would mention statements such as: "I would expect my employees to continue to work within the best of their ability", "I'd expect them to stay well – they would need to manage their illness and their medication", "I'd expect them not to take advantage of the situation".

In Project Empower's experience successful workplace responses to HIV and AIDS create an environment that supports HIV-positive staff to remain healthy and continue working. HIV-positive employees are empowered to manage their illness and take responsibility for their health. Management expect HIV-positive employees to take their treatment as prescribed, go for CD4 counts (which monitors the person's immune system, and informs whether and when to start treatment; once on treatment, it measures the effectiveness of that treatment) and seek treatment for opportunistic infections. In some instances, this was incorporated into the appraisal process. Within the workplace support given to an employee, they were expected to carry on working in the same way as before they disclosed their HIV status.

### **Dealing with unrealistic demands**

Sometimes unrealistic or inappropriate demands surfaced. In one workshop a

participant stated, “if I were HIV-positive, I would want a car to go to the clinic whenever I want”. Understandably this is not a benefit that managers can support. The point of an HIV workplace policy is to ensure the organisation’s long-term sustainability.

Resources should therefore be used wisely to benefit the organisation’s work. As Laura says, “If the organisation’s cars are being used all the time for transporting staff, then the mission suffers, the organisation’s reputation dwindles and in time there will no jobs for anyone!”

To deal with such demands, participants were encouraged to think about how they would respond if they were a manager. Participants discuss how the organisation uses its resources and form a collective set of agreed demands. Unrealistic demands are toned down but more constructively, innovative ideas are explored about how to address some seemingly unrealistic demands.

#### **4. If you were the organisation’s management, what would you like to offer an HIV positive employee?**

When employees put themselves in the shoes of their management team and considered what they would like to offer an HIV-positive employee they found that, by and large, the benefits would be completely free or with minimal costs.

Support, solidarity and creating a ‘safe’ confidential and respectful environment were as important as time to attend clinic appointments and sick leave. People said that access to up-to-date information on HIV and AIDS was most important, along with contributions to medical aid schemes. Whilst there are some direct or indirect costs attached to these, others rest on staff attitudes, commitment and, as Mpume says, “the political will of management”.

#### **5. Given the resources available, what can be offered?**

We have all been there. We work in resource poor environments. We write proposal after proposal, we contact donors and funders and we are made to feel lucky if we hear back from just one. We struggle for funding and often the

grants we receive do not include salaries, office rentals and other ‘overheads’. The thought of trying to fund an internal HIV workplace response can be worrying and overwhelming.

As facilitators it would be easy (and less stressful!) to gloss over the difficult issue of money and where to allocate the minimal funds available. Project Empower however, build this issue into their workshops. Decisions about what should be funded are discussed between all staff – volunteers, employees, management and, where possible, board members. Collective decisions are made and everyone has the opportunity to contribute.

By the time participants get to the question of funding, the policy will have started to take shape. The work of previous sessions will have formed the list of benefits and responsibilities that make up the bulk of the workplace policy. Participants then look at what money is available in the budget – a document usually available internally – and what can be allocated to funding the workplace policy. By collectively agreeing the priority areas of the policy, rational decisions can be made and conflict between staff and management can be reduced. As Laura and Mpume discussed, this session is “constructive rather than divisive”. Crucially, by this point, it will have become clear that there are many changes that can be made to build an HIV-positive organisation that are completely free of any cost.

#### **A written output**

Although it is the process that is most important, the workplace response must be written down into a formal policy document. The written policy serves as a reminder to the organisation about what they had agreed during the workshops.

A participant in the process and Director of a local NGO reflected, “people felt good to be part of a process. It boosted peoples’ self esteem, they had drafted the policy themselves.” This sentiment was echoed again as, “staff are happy because [the policy] was developed and owned by them and not imposed, it is completely relevant to

the situation in our organisation. Staff feel proud to have been a part of the process because we made a contribution and learnt from it. Because of the process things have changed". Employees felt empowered to see their ideas, words and important issues transformed into the policy that would set the direction of the organisation's response to HIV and AIDS.

## Challenges

Any process that deals with people, sensitive issues and financial commitments will raise difficult challenges. Project Empower found the following:

### 1. High staff turnover

The main challenge is high staff turnover. The process is long and many different stages of development are journeyed. During this time staff may leave the organisation and new employees join. New staff and management may not fully appreciate the work that was done to form the policy. If no attention is drawn to the policy, they may not even know it exists.

Project Empower found that NGOs with sustainable and successful workplace responses were able to address this issue. New employees were thoroughly oriented in the HIV workplace policy. They were required not only to read the policy, but to discuss and comment on it. In doing so they learnt about the process and the spirit in which the policy was written. They also had the opportunity to become engaged with the workplace response through discussion and critique.

### 2. A lifeless policy or a living response?

As Laura explains, "you can't just do the process once and leave it at that." Over time new laws are enacted, revised guidelines emerge and employees' circumstances change. The HIV workplace policy must be revisited and amended through a structured process every year. This keeps it fresh and up-to-date and enables new staff to be included. A policy and a process that are not revisited frequently will lead to a workplace

response that is out of date and is lifeless in character.

### 3. Opening Pandora's Box

The process by its very nature can raise many other organisational development issues which are not directly related to HIV and AIDS in the workplace. Facilitators may feel pressure to solve all the organisation's problems and may feel the confidence of employees slip away when they cannot do so.

Project Empower facilitators found themselves in this situation several times during the course of the project. As Laura says, "facilitators must be clear about what organisational development issues they can handle and what they can't, and be up front about this from the beginning." In several cases, participation in Project Empower's workshops led to unforeseen positive outcomes in other areas of the organisation.

As the Director of one organisation recalls:

"the process helped the organisation to open up to other issues like gender and things that affect staff outside of work hours such as drinking and financial management of personal funds. Because of the [HIV workplace] policy and the opening up of a space for discussion about issues, we now have a culture of openness that has carried on. We have quarterly meetings which did not happen before. We had never really interrogated whether the values we were teaching in the community were really believed internally. These meetings helped bring clarity about what the organisation believes in."

### 4. Lack of information

It is easy to assume that the participants will have a wide ranging knowledge about HIV and AIDS. This can be far from the truth. "What came out of the process was a hunger for information" explain Mpume and Laura. Participants had limited access to accurate information and this had, in some cases, clouded their judgement about what they should be entitled to as part of a



workplace response to HIV and AIDS. As one participant explains, “We had preconceived ideas about what our organisation should provide. We thought management should pay into a medical scheme. But the scheme was not as simple as we had originally thought.”

The important point is to move at the organisation’s pace. If this means going over basic information about HIV and AIDS before moving on to talking about a workplace response then that is what must be done.

The HIV workplace policy must also address this issue. The policy must set out how information on HIV and AIDS will be continually collected, updated and displayed. Where a focal point person is responsible for doing this work, it must be included in the job description and form part of the performance appraisal.

## 5. Flexible funding

Laura and Mpume recognise that they were considerably helped by an understanding donor willing to fund a long term project with unpredictable outcomes. The very process of moving at the client organisation’s pace meant scheduling additional workshops and changing the planned timeframe. Few donors are flexible enough to allow this.

Is it too much to expect donors to change their funding criteria to enable long term unpredictable processes? If they are serious about supporting organisations to respond to HIV and AIDS in the workplace, should they be changing their way of thinking about HIV workplace policy development? Is this realistic? Perhaps not, in the short term. However, donors who ask for the HIV workplace policy as part of their funding assessments should look less at the policy and more at the evidence of how the policy was developed. This could create a compelling incentive for a more participatory approach to policy development.

## Conclusion

As this Praxis Note has shown, if we are serious about the importance of HIV workplace policies, we must also be serious about the methods used to develop them. The success of an HIV workplace policy relies entirely on addressing the attitudes and behaviours of the *people* that make up an organisation’s workforce. We must therefore personalise HIV and AIDS in the workplace and put *people* at the centre of the process. Crucially, we must move at the pace of the organisation not at the pace of the log frame.

All this takes time, energy and good sound facilitation. In developing HIV workplace policies, we are not looking to create a policy document that sits in a file on a bookshelf. We are looking for an active engaging response. A response that builds HIV-positive organisations that are strong, resilient and able to effectively respond to HIV and AIDS in the workplace.

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<sup>i</sup> Praxis Note 38, ‘Denial, fear and fatigue: The emotional blocks to addressing HIV AND AIDS in the workplace’, By INTRAC and Project Empower, June 2008 ([www.intrac.org/resources.php?action=resource&id=466](http://www.intrac.org/resources.php?action=resource&id=466))

<sup>ii</sup> Adapted from ‘Building HIV positive organisations: Lived realities’ by Laura Washington and Allan Moolman. By Project Empower (undated).