



> **Allan Moolman**, guest editor for the thematic section of this magazine on:

## Internal HIV/AIDS mainstreaming

This is the very first issue of *Exchange*, a magazine on HIV/AIDS from the perspective of gender, sexuality and sexual health. It is the successor to *Sexual Health Exchange*, which was published by the Royal Tropical Institute in the Netherlands for many years. We decided to change the design, content and title to celebrate and accommodate a new partnership with Novib (Oxfam Netherlands).

In *Exchange*, several articles on one overall theme have been produced by Oxfam counterparts in the framework of the KIC project (see page 2). One of these counterparts has been invited as a guest editor to this thematic section: Allan Moolman of Project Empower in Durban, South Africa. Together we invited several people working in NGOs in Africa to share their experiences, knowledge and insights on how to address HIV/AIDS in civil society organizations.

In addition, several articles have been collected on a variety of subjects, including the lack of access to prevention and treatment for mobile population groups such as fishermen and temporary migrants and the consequences of abstinence-only programmes for sexual minorities. In this first issue of *Exchange*, particular attention has been paid to initiatives and programmes in South Africa.

We wish you good reading and welcome your comments!

**Nel van Beelen**  
Managing editor

**Allan Moolman**  
Guest editor



**Youth and the media in South Africa** p.18



**Mobility and HIV/AIDS** p.23

## Managing HIV/AIDS in the civil society workplace

**While the majority of civil society organizations (CSOs) have a good understanding of the potential impact of HIV and AIDS on the communities with whom they work, very few have examined the impact of the epidemic on their own staff. Fewer CSOs have formulated even a basic response to the potential crisis that HIV and AIDS present. Mainly CSOs in Southern countries, the epicentre of the epidemic, find themselves in a precarious position.**

Low staff numbers and high reliance on volunteers make non-profit organizations particularly vulnerable, should members of staff be HIV positive. These organizations deliver critical services to marginalized communities and, therefore, any threat to their survival places communities they serve at even greater risk. The pandemic has the potential to devastate organizations that are often the only lifeline for many people.

The responses to the impact of HIV/AIDS on the workplace have largely been technical. Driven by the corporate sector's need to maintain its productive capacity, mainstreaming efforts have focused on the provision of antiretroviral treatment (ART) and workplace programmes addressing employee health needs. Many CSOs, under pressure from the donor community, have acceded to the demands to mainstream HIV/AIDS, by rapidly adopting corporate sector policy models and practices without much consideration for the applicability or

sustainability. Mainstreaming has become a catchphrase, with little meaning or understanding attached to its use.

Mainstreaming HIV/AIDS in CSOs requires that organizations consider and respond to the impact on the constituencies they serve through their programme work as well as the impact on the lives of their own staff and ability to continue delivering services once they are affected by HIV and AIDS. Mainstreaming requires that we consider the implications HIV/AIDS has for our work – that we are conscious of the effects the epidemic has on our organizations and, in turn, the effect our work has on the epidemic (see Box on p.4).

### The role of workplace policies

The International Labour Organization (ILO) has produced a comprehensive guideline for policy development that, coupled with the provisions in local labour and human rights legislation, provides workers with access to



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a number of policy tools.<sup>1</sup> Developing policy based on the principles outlined in the ILO Code of Good Practice is straightforward. What has largely been missing from the discourse is that policy is only one component of organizational response. A workplace policy has to be applied in a supportive and enabling environment. The reality is that stigma exists in many organizations and policy alone cannot address it.

This is a critical issue. Even with the best policy it is quite common to hear that staff in organizations are not taking up the benefits on offer. Stigma is also contextual; what is stigmatizing in one situation may not be in another. A participant in a workshop pointed out that stigma, whether it is real or perceived, is a reality for the person experiencing it. This statement challenges us to look critically at our practices and to question whether through development work we may be creating more stigmatizing environments. For example, a programme that can only be used by HIV-positive people can draw unwanted attention to them. Inside the organization, stigma poses a barrier to disclosure and thus influences the taking up of available benefits and services, which makes guaranteeing confidentiality even more important.

There is a general assumption, as with HIV/AIDS, that all organizations understand gender. It is an often forgotten component of the impact assessment process. It is well known that HIV and AIDS do affect women disproportionately. Women do bear the burden of care and are more vulnerable to

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**KIC**

### **Knowledge Infrastructure with and between Counterparts (KIC)**

Novib (Oxfam Netherlands) and *Exchange* are collaborating to improve and boost learning on HIV/AIDS between Oxfam counterparts. For the coming issues of *Exchange* Oxfam's counterparts are invited to share ideas for themes and to write articles about the lessons learned: good, bad and new practices on HIV/AIDS. The articles produced in the framework of this collaboration are accompanied by an Oxfam logo in a green title box.

Besides using *Exchange*, the KIC project has an interactive website under construction where Oxfam counterparts can share evidenced-based practices and lessons learned. Awaiting the portal, counterparts are encouraged to use the e-mail address [aids.kic@novib.nl](mailto:aids.kic@novib.nl) for sending reactions and lessons learned on HIV/AIDS mainstreaming and for questions/comments about this edition.

HIV infection for biological, social and economic reasons. What is often not recognized is that men and women may cope differently with the disease and that this may affect their uptake of VCT, their disclosing behaviour and their access to and use of treatment and HIV management services. Also, men and women may respond differently to HIV prevention messages and may have different preferences for settings and ways in which these messages are conveyed. It is thus critical to the success of workplace programmes that the gendered impact of HIV and AIDS, and the gendered response of workers, is taken into consideration.

### Finding solutions

Many CSOs lack the resources to design and implement large scale health-focussed interventions. They simply lack the financial and income-generating capacity to provide treatment and medical care and support. Some constraints experienced by small organizations are:

- providing or facilitating access to ART in countries where this treatment is not available through health insurance or medical aid packages,
- facilitating access to VCT and HIV management in regions where there is



Discussing HIV/AIDS with colleagues

Photo: Gender AIDS Forum, South Africa

- a general lack of health services,
- implementing exit policies (continuing to pay for treatment after a person left the organization), etc.

Sometimes painful decisions have to be made, e.g., on whether workplace policies should cover dependents of staff (family

### There is a need to move away from general, one-size-fits-all approaches to mainstreaming

members) and to what degree, and also volunteers. Another important issue is how to make sure people entitled to the benefits

will receive them without being forced to disclose their status to colleagues they do not wish to disclose to. Different organizations have found different solutions to address this issue, ranging from restricting access to all private information to only one person in the organization, to negotiating with health services that they send anonymized bills, handing out vouchers for VCT or other HIV/AIDS-related services, or contracting specialized firms or NGOs to support and assist HIV-positive staff members.

Solutions have to be tailored within the constraints of available resources. Workplace policies and available financial and human resources have to complement each other. What CSOs have to remember is that they have a wealth of experience, skills and information available to them in their own organizations and in peer networks. The challenge to them is to put these resources to use to create and sustain positive work environments.

Responding to HIV/AIDS is not a simple matter – nor are there simple solutions. The impact of HIV/AIDS on organizations is complex and contextual. While the effects on staff may be similar, the impact on organizations will vary – as will responses. The response of individual organizations will be limited by their access to resources and the culture and day-to-day practice of the people who constitute these organizations. A sound response begins with an honest

### HIV/AIDS and the workplace: some facts

- By the end of 2003, globally as many as 36.5 million persons who are engaged in some form of productive activity were HIV positive.
- By 2005, over two million labour force participants will be unable to work at any time as result of HIV/AIDS, and by 2015, well over four million.
- In several African countries, there are over a million economically active persons who are HIV positive: e.g., in Nigeria, 2.4 million workers are HIV positive, in South Africa, nearly 3.7 million. Kenya has 1 million, Mozambique 1.1 million, Ethiopia and Zimbabwe 1.3 million each, and the United Republic of Tanzania 1.4 million.
- The ILO also estimates that, globally, the combined impact of the deaths and illness of persons living with HIV/AIDS will add 1% to the economic burden and just over 1% to the social burden by 2015.

*Source: HIV/AIDS and work: global estimates, impact and response – 2004. The ILO Programme on HIV/AIDS and the World of Work, ILO, 2004: [www.ilo.org/public/english/protection/trav/aids/publ/global\\_est/glob\\_report\\_2004rev.pdf](http://www.ilo.org/public/english/protection/trav/aids/publ/global_est/glob_report_2004rev.pdf)*



## Developing a workplace programme

We need more than organizations that have mainstreamed HIV/AIDS; we need to have mainstreamed HIV/AIDS throughout our society. This requires a concerted

assessment of an organization's, and individuals' vulnerability to HIV infection. There is a need to move away from general, one-size-fits-all approaches to mainstreaming. Organizations' individual needs are different and the responses in support of their efforts to mainstream HIV/AIDS need to suit their circumstances.

effort and cooperation on the part of the international community, governments, the corporate sector, civil society and our communities to address HIV/AIDS. This should happen not only in high-prevalence countries but also in countries where the impact of AIDS is not yet that visible. We should all be more conscious of the need to

act to avert a crisis in CSOs and in the communities they work with, and in.

Increasingly, the burden of service delivery to poor communities is being transferred to CSOs, and a threat to the survival of these organizations represents a threat to many communities in crisis. It is vital that CSOs recognise the need to rethink the way they deliver development and health programmes to affected communities and this, most importantly, requires a shift in how they conceptualise themselves and how they relate to themselves. Developing a workplace programme – which should be a continuous process rather than a one-off affair – is a first step in this transformation process.

There are a growing number of effective efforts to slow the epidemic's advance. But there is no magic bullet, no single formula that works everywhere. An effective organizational response depends on a combination of prevention and treatment, as well as programmes to address the present and future impacts of AIDS. The ability of CSOs to deal with HIV/AIDS and its effects will have as much to do with their ability to constructively engage with, and relate to, each other as it will to their workplace policies. ■

*This article was produced as part of the KIC project.*

### About internal mainstreaming

Mainstreaming HIV/AIDS is a tool to achieve an expanded cross-sectoral approach to HIV/AIDS. It is about incorporating HIV/AIDS in the core business of organizations. Mainstreaming refers to all interventions that in one way or another address HIV/AIDS and can be helpful in reducing the transmission or impact. *Internal* mainstreaming is about workplace policies and programmes. It focuses on the vulnerability and risks of the organization itself and on the people within the organization. *External* mainstreaming is incorporating HIV/AIDS into the core business of an organization and its programmes.

The output of internal mainstreaming is a workplace programme comprising in-house prevention, care and capacity building. Internal mainstreaming is important not only because of maintaining the health and wellbeing of the personnel and the sustainability of the programme and interventions, but also in building the necessary expertise and capacity for an effective HIV/AIDS community programme for the beneficiaries. Internal mainstreaming is an important entry and starting point for external mainstreaming. Capacity building of the organization and its staff puts staff and workers into a better position to understand what can be done in the programmes.

According to the book *AIDS on the agenda* by Sue Holden,<sup>1</sup> three main strategies of internal mainstreaming are:

1. *Awareness-raising and staff education, e.g.:*
  - by involving PLWHA,
  - by providing ongoing training – repeated sessions for new and old staff,
  - by developing tailored sessions (single-sex, various levels of staff, etc.), if possible,
  - by working with an HIV/AIDS focal point and/or peer educators.
2. *Encouraging and facilitating access to VCT, for example:*
  - by referring staff to an AIDS Service Organization (ASO) to ensure confidentiality,
  - by introducing role models, e.g., people who live positively with HIV/AIDS, or higher level staff going for VCT.
3. *Development of a workplace policy by writing up what type of services are offered, including:*
  - HIV/AIDS training and awareness sessions,
  - access to VCT,
  - special AIDS-related human resources and personnel policies (e.g., health schemes including access to ART, arrangements for sick leave, and conditions of employment for HIV-positive staff members).

1. S. Holden, *AIDS on the agenda*. Oxfam, 2003 (256 p.): [www.oxfam.org.uk/what\\_we\\_do/issues/hivaids/aidsagenda.htm](http://www.oxfam.org.uk/what_we_do/issues/hivaids/aidsagenda.htm)

### Allan Moolman

Coordinator Project Empower (Durban, South Africa) and guest editor of this issue

#### Correspondence:

Room 234 Diakonia Centre  
20 St Andrews Street, Durban 4001  
South Africa  
tel: +27 31 3103565  
fax: +27 31 3103566  
e-mail: [info@projectempower.org.za](mailto:info@projectempower.org.za)

1. *Implementing the ILO Code of Practice on HIV/AIDS and the world of work: an education and training manual*. ILO Programme on HIV/AIDS and the World of Work, 2002 (329 p.): [www.ilo.org/public/english/protection/trav/aids/publ/manual.htm](http://www.ilo.org/public/english/protection/trav/aids/publ/manual.htm) (available in English, French and Spanish)



# Living with HIV in an HIV-negative workplace

**The experiences of Phindile, a woman living with HIV in South Africa**

*Article produced as part of the KIC project*

**Living with HIV is not easy, especially if you are the only HIV-positive employee in an organization in which the rest of the staff are HIV negative or do not know their status. There is always a feeling of guilt and envy for not being negative like other workmates.**

Whether they are on antiretroviral therapy or not, what HIV-positive employees need most is support by their colleagues. Unfortunately, colleagues often show more sympathy than support. This is not easily accepted by HIV-positive people because they eventually stigmatize themselves instead of being encouraged by the support. It is necessary for everyone in the organization to clearly understand how to treat an HIV-positive colleague. Both the HIV negative and positive need to know how and when to act to support and care for each other.

## Ups and downs

As an HIV-positive employee I experience good and bad moments. There are times when I fail to cope physically. I sometimes experience unbearable headaches, sore eyes, running tummy/diarrhoea, nausea or just fatigue and it is during this time that I need a break from work. During these periods I feel physically able to perform only the least physical tasks. Trying to work when I am feeling like this worsens my situation. Often the only action that will help is going home to rest until I am ready to work productively again.

Emotionally, I sometimes feel low when I am sad, upset or even frustrated. It is hard to concentrate, be friendly and respond positively when someone tries to reach out and help. I feel guilty about this and do not want to burden my colleagues. HIV-positive people are likely to be more emotional than other people because of the

anger and frustration created through being sickly and the ever-present fear of death, rejection and shame.

I sometimes worry about my ability to meet work challenges. I wonder whether my colleagues have any confidence in my ability to fulfil my job requirements and I am afraid to let them down. At times it is not even easy to say no, to admit that I cannot undertake a particular task. However, this should not affect my colleagues' work in any way. Taking time off should not inconvenience or have a negative impact on the organization's work or my colleagues. As much as one does not plan to get sick, taking extra time off should be compensated for in some form. It's not easy though because whenever I am off sick, my body is at home

**We need to step in each others' shoes and build a conducive working environment that is healthy for all employees**

but I keep thinking about what I should be doing at work. Yet I know that this does not help, because I should avoid any form of stress in order to be fit and ready to work again.

## Some practical solutions

Policies/guidelines should be put in place to address such situations. In cases where someone is unable to perform under normal work routines, alternative work practices should be explored. A central issue is fatigue. This is an effect of antiretroviral treatment as well as a

# Resources

## on internal mainstreaming

### Mainstreaming HIV/AIDS in practice.

*A toolkit with a collection of resources, checklists and examples on CD Rom for SDC and its partners*  
Swiss Agency for Development and Cooperation (SDC/DSC), 2004 (56 p.)



This toolkit offers a five-step approach to mainstreaming HIV/AIDS. The first three steps are linked to preparatory analysis of the situation and include: context and organizational analysis, analysing the impact of HIV/AIDS on what you do, and analysing the potential negative implications of what you do on HIV/AIDS. Step four is to develop a comprehensive Workplace Policy and Programme and step five is to plan and implement this policy.

[www.deza.ch/ressources/deza\\_product\\_en\\_1280.pdf](http://www.deza.ch/ressources/deza_product_en_1280.pdf)

### Working positively:

*A guide for NGOs managing HIV/AIDS in the workplace*  
UK Consortium on AIDS and International Development, 2003 (26 p.)



This guide looks at the key issues involved in developing a workplace strategy and at how different NGOs and commercial companies are approaching these issues. It also provides a guide to the key components of a successful strategy and a list of useful reference documents.

[www.aidsconsortium.org.uk/public.html](http://www.aidsconsortium.org.uk/public.html)

consequence of the normal course of living with HIV. There are some practical things that can be done to accommodate treatment regimes, e.g., having short breaks during extended meetings. This is important because one who is taking medication and antiretrovirals needs optimum absorption, balanced meals and plenty of rest.

Treatment regimes have a number of side-effects, which may be mild or need a little extra attention. For example, if I am having persistent headaches, fatigue, etc., reading or work that requires thorough thinking can be substituted by less taxing tasks. I am fortunate enough to be on anti-retrovirals. It would have been very hard for my organization and I if this were not the case because drugs are a bit expensive and require continuous use. There is a need, though, for a medical aid scheme of some sort to cater for provisional needs such as visiting doctors.

It would also be important for the organization to have procedures on how to act in serious situations. I think basic First Aid training is needed to cater for HIV-related emergencies. For example, if I accidentally cut myself while on duty, blood will come out. With the First Aid kit (which should include latex gloves, etc.), someone can handle that instead of panicking or calling 911. This training, I think, would enable all staff to know exactly what to do while ensuring that they do not contract HIV.

### Understanding the risks and dangers

The concern expressed is often that I present an infection risk to my colleagues and that precautions should be taken not to transmit HIV to them. While this is true, many people do not realize the danger they present to HIV-positive staff members. Having a cold or flu is considered to be a normal occurrence for most people. These are infections that we all have and get over. We are often not conscious of the fact that such common infections like this could be life-threatening to a PLWHA.

People in workplaces should talk to each other more. We need to, at a very practical level, understand what the risks and dangers of HIV in the workplace are. We also need to step into each others' shoes and build a conducive working environment that is healthy for all employees. ■

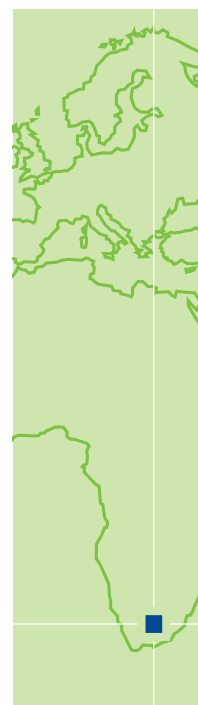
### Phindile (not her real name)

works in a small capacity building NGO in South Africa

Correspondence:

Phindile, c/o the editor of *Exchange*

e-mail: [exchange@kit.nl](mailto:exchange@kit.nl)



# The need for being flexible in implementing workplace policies

**The experiences of Vicci Tallis of Gender AIDS Forum, South Africa**



*Article produced as part of the KIC project*

**Gender AIDS Forum is an activist NGO based in South Africa and focuses on the interface between HIV/AIDS and gender. In 2003, after a strategic planning process, which was a watershed moment for the organization that was established in 1999, we started addressing the issue of policy development, including how to tackle HIV and AIDS in the workplace.**

We are a flat-structured organization, which means that the Board, staff and volunteers are equal and make decisions as a team. Through a consultative process we decided on two approaches to addressing HIV and AIDS, that is within the Conditions of Service and also in our Gender and Diversity policy. The policy development process involved a designated Board member and staff member drafting the policies, which were then circulated to the rest of the Board, staff and volunteers.

Within the organization we have people who have been integrally involved in mainstreaming HIV and AIDS into the programmes and policies of NGOs. Their skills were useful in developing our own approach. Written comments from the Board, staff and volunteers were collected and then integrated into the policies. Finally, the changes were discussed at a meeting and the policies adopted.

## Conditions of Service

Within the Conditions of Service we reflected on issues such as compassionate leave and sick leave using an HIV and AIDS lens and debated what would be fair and just but at the same time would ensure that the work of Gender AIDS Forum is not compromised. These debates are not always easy and it is only when faced with the realities of HIV and AIDS that the provisions in the policy are tested.

We quickly had to put the policy to the test when one of our volunteers, a woman who had worked for the organization on an almost daily basis and was on government pension, fell sick in July 2004 and died a month later. She had little household or family support. We had a policy that did not reflect these realities of a

volunteer, but an organizational culture based on our beliefs and principles that the inside is as important as the outside. We paid for her hospitalization, medication and contributed to her funeral. One year on, we still had a relationship with her eldest child and provided for him. The greatest lesson learned was the need for flexibility in order to be responsive to the situations that you are faced with and which don't necessarily match the policy. The emotional impact of a Board member, staff member or volunteer who is sick, or who dies, should not be underestimated and should be dealt with.

## Gender and diversity policy

We are an organization that is diverse in terms of gender, race, sexual orientation, HIV status – representing different marginalized groups. We felt it was important to include HIV status in our diversity policy to ensure the rights of men and women living with HIV and AIDS, and in keeping with our focus on building solidarity

**The greatest lesson learned was the need for flexibility in order to be responsive to the situations that you are faced with and which don't necessarily match the policy**

with different marginalized groups. We have people living with HIV/AIDS on our Board as well as staff. Some have been actively recruited because of their HIV status and our policy is to expand the number of diverse groups represented in the organization. Some people within the Board and staff are openly living with HIV/AIDS whilst others prefer to keep their HIV status to themselves.

Part of our policy refers to the fact that it is obviously not compulsory to disclose HIV status to the rest of the team. However, our recent negotiations with medical aid companies to ensure that all staff receive medical benefits has necessitated people to disclose



Vicci Tallis

their HIV status to the member of staff coordinating the process. Medical benefits for people living with HIV/AIDS are difficult to source and some companies flatly refuse to enrol HIV-positive people. As an organization we had to negotiate the best possible package, which addressed the needs of HIV-positive and HIV-negative colleagues and of those of us who do not yet know our status.

This had to be discussed and agreed amongst the team – especially since the best option for HIV-positive people in the organization who joined the medical aid was a one-year exclusion from benefits for

any existing condition related to HIV and AIDS. During the first year, only non-HIV-related illness and accidents are covered by the medical aid; however, children are exempted from this exclusion. Applying the principles of justice, fairness and equality, which underpin our gender and diversity policy, can sometimes be a challenge.

A policy may be a good starting point for an NGO to address the realities and impacts of HIV and AIDS. However, the policy should never be so rigid that it fails to deal with the complexities of the HIV and AIDS epidemics. A clearly defined organizational culture that espouses openness, trust and a safe space will go a long way to creating a conducive environment in which the implementation of the policy can be more effective. ■

### Vicci Tallis

is coordinator with Gender AIDS Forum, an activist feminist NGO in Durban, South Africa

#### Correspondence:

1101 Sangro House, 417 Smith Street  
Durban 4000, South Africa

tel: +27 31 3071253, fax: +27 31 3071254

e-mail: [vicci@gaf.org.za](mailto:vicci@gaf.org.za), web: [www.gaf.org.za](http://www.gaf.org.za)

## Resources on internal mainstreaming

### Managing HIV/AIDS in the workplace:

*Examples of nine non-governmental organisations in South Africa, Zambia, and Zimbabwe*

Mary O'Grady, Oxfam International, 2004 (37 p.)



*Managing HIV/AIDS in the workplace* is based on a study of nine NGOs in three countries. The results show that the impact of HIV/AIDS on NGOs is extensive. The lessons shared are on a range of different areas: workplace policies, training, human resource and financial implications as well as the area of NGO sustainability. One of the central recommendations is the need for greater dialogue between NGOs and their funders on the issue of support to develop workplace strategies but to also enable successful implementation of these policy intentions.

[www.oxfam.org/eng/policy\\_pape\\_HIV.htm](http://www.oxfam.org/eng/policy_pape_HIV.htm)

### Positive organisation:

*Living and working with the invisible impact of HIV/Aids – a resource for NGOs*

H. de Wet, C. Everett, CDRA, 2003 (144 p.)

What will it take to build organizations that are robust enough to absorb the impacts of the AIDS epidemic, while providing humane, stable workplaces? A practical resource for NGOs, this book contains six sections, which can be read individually or in sequence:

- a conceptual overview of the epidemic,
- a research report into the experiences of South African NGOs affected by the epidemic,
- a guide to the South African legal and policy framework,
- methodology for NGOs adapting to the HIV/AIDS environment,
- a practical toolkit for responding to HIV/AIDS,
- an annotated bibliography and references to key websites.

Hardcopy: [www.cdra.org.za/Bookshop/BookOrderForm.htm](http://www.cdra.org.za/Bookshop/BookOrderForm.htm) or [info@cdra.org.za](mailto:info@cdra.org.za)  
(\$21 incl. postage)



# Developing a workplace programme

The experiences of Ticharwa Masimira of MASO, Zimbabwe



Ticharwa Masimira

*Article produced as part of the KIC project*

**It all started with one of our funders, GTZ Zimbabwe, inviting their partners to a workplace policy development workshop to share ideas on how to respond to HIV/AIDS from the perspective of an AIDS Service Organization (ASO). At that time Midlands AIDS Service Organisation (MASO), given its experience with an HIV-positive employee, was already toying with the idea of drafting a policy to respond better to the situation, the future, and HIV/AIDS education and awareness for all staff.**

We also realized that while programme staff were fully knowledgeable about HIV/AIDS issues, challenges and implications, non-programme staff like drivers, secretaries and administrative staff had a number of knowledge gaps, which needed to be addressed. About the same time, staff were beginning to worry about their future should they be infected. All these issues motivated us to develop a workplace programme and policy.



At the time we hired Frank Guni, a man who was openly living with HIV, there had been an outcry nationally from people living with HIV/AIDS (PLWHAs) and other stakeholders over the need for ASOs to 'walk the talk' by openly creating jobs and employing PLWHAs. It had been argued that doing so would send a positive message about the good intentions of ASOs. On the other hand, PLWHAs themselves felt this would open doors for them to share practical experiences on living with HIV/AIDS with both the infected and affected. Frank had initially been co-opted as a member of our executive board and later as an employee serving as coordinator of our Community Home-based Care Programme. In employing him, we looked at both his

HIV status and qualifications including his experience having worked for the Red Cross Society in Zimbabwe.

Our major expectation from Frank besides being suitably qualified and experienced was to practice what we preached by showing the community that this could be done. In addition, this was our way of fighting the stigma and discrimination associated at that time (1996) with embracing PLWHAs. When I first mentioned my intention to hire an HIV-positive person, there was some uneasiness from some staff initially. However, following discussions with all concerned, Frank was accepted easily into the organization. Fears of the unknown, in this case 'getting infected by him,' were

**One of the main things we have learned is that developing and having this policy is not the end**

dispelled by education. When I took the decision to employ him I expected some resistance because this was a new development for not only MASO but other organizations in Zimbabwe as well.

## Learnings and lessons

In developing a workplace programme, we researched and exchanged information with others including attending workshops. Assisted by the Programme Manager and the Chairperson of the Board, I started the programme in 2004. Following conscientization on the importance of prevention, the staff became committed because they knew that their enhanced knowledge

## Resources on internal mainstreaming

### VSO Mainstreaming Guide

2004 (40 p)



A manual especially developed for VSO programme offices but also useful for other organizations. The guide is divided into two main sections. The first provides background information on the concept of mainstreaming, including a model developed by VSO staff. The second section outlines the six stages for mainstreaming HIV/AIDS, as set out in the model.

[www.vso.org.uk/textonly/Images/mainstreaming\\_guide\\_tcm9-4795.pdf](http://www.vso.org.uk/textonly/Images/mainstreaming_guide_tcm9-4795.pdf)

### Charting the road from policy development to implementation

*Processes, experiences and lessons from southern Africa*

(DVD & Users' Guide)

Oxfam/CARE, 2006



While there are an increasing number of resources on how to develop HIV/AIDS workplace policies, less has been documented and shared on the actual workings and practical issues of policy implementation, be it from an NGO or private sector point of view. Oxfam has partnered with CARE USA in southern Africa in documenting workplace policy implementation in the form of a DVD with actual interviews of staff, managers and service providers and users. The DVD is broken down into a number of chapters – background and policy formulation; policy implementation; challenges; and work in progress – giving the viewer freedom to choose whichever area interests him/her. The DVD will be accompanied with a Users' Guide that will include copies of documentation developed by each agency. This resource targets any manager involved in developing and managing human resources, in the NGO, public or private sector. It will be available on the market from March/April 2006.

For more information contact Dolar Vasani, regional HIV/AIDS advisor, e-mail: [dolar.vasani@novib.nl](mailto:dolar.vasani@novib.nl)

would help them to become peer educators to their friends, relatives and the community at large. Their response to the workplace programme was as if they were being taught what they already knew, only to discover that there was a lot more to learn. My personal lessons learned from the whole experience were:

- that a leader must take decisive action regardless of the outcome,
- that we must not be prejudiced as this closes windows of opportunity,
- that a leader can be pivotal to influencing 'courage, change and acceptance' to other staff in dealing with fear, stigma and discrimination.

The setting-up of workplace policies is a new development in Zimbabwe with AIDS Service Organizations coming up with their own documents. MASO also has a

"I believe that our workplace policy and programme could be improved by learning and exchanging information and practices with other organizations"

written policy. One of the main things we have learned is that developing and having this policy is not the end. It is the implementation part in terms of resources that is difficult, especially as it relates to extra payment to cover AIDS-related costs. The programme implementation can easily be integrated into organizational activities, resources permitting. However, provision of extra resources is the only solution as part of the overall budget needs.

I believe that our workplace policy and programme could be improved by learning and exchanging information and practices with other organizations. We also have a need for hiring experts/consultants to assist us to improve on what we are currently implementing. ■

### Ticharwa Masimira

Chief Executive Officer MASO (Midlands AIDS Service Organisation), Gweru, Zimbabwe

Correspondence:

PO Box 880 Gweru, Zimbabwe

tel: +263 54 50536, fax: +263 54 50377

e-mail: [maso@adtech.co.zw](mailto:maso@adtech.co.zw)



# Building HIV-positive organizations in South Africa

## The role of sharing experiences and results

Article produced as part of the KIC project

Allan Moolman

During 2003, Project Empower, in collaboration with the Health Economics HIV/AIDS Research Division (HEARD) of the University of KwaZulu Natal, began a process of exploring ways in which civil society organizations (CSOs) could learn to live with HIV. We worked with 10 KwaZulu Natal-based non-governmental organizations (NGOs) and community-based organizations (CBOs) to construct a clearer picture of the implications that the epidemic has for the internal workings and sustainability of these organizations.

Located in eastern South Africa, KwaZulu Natal province has one of the highest HIV prevalences in the country. The Leadership Forum, as the programme was titled, brought together a mix of both rural and urban CSOs that ranged in size from CBOs and NGOs with small, localized communities, to NGOs working province-wide.

None of the organizations that participated in the forum focus directly on HIV/AIDS service delivery, although all have had some experience of working with HIV-positive people. All participants in the process were in leadership positions in their organizations. Organizations were specifically asked to nominate a representative who had the authority to influence the organization's planning and management processes. Participants interacted in a number of learning sessions over a nine-month period ending in September 2003.

As a result of this process organizations have begun to understand and deal with the fact that the epidemic has devastating

economic implications, but more significantly, understand and agree that it is the social fabric (the relationships that make organizations function) that is going to change and a significant effort has to be made to develop new ways of relating.

### Assumptions and principles

In undertaking this work, Project Empower made a few fundamental assumptions about finding organizational solutions to the problems of HIV and AIDS. Solution-finding is a process that requires that we:

- understand our organizations,
- predict the potential impact of HIV/AIDS,
- propose and test a number of strategies to deal with this impact,
- share our learning and experiences of working on HIV and AIDS, and
- constantly review and adapt our initiatives in the light of new learning and experience.

With these premises underpinning the programme, the following principles were used to guide the structure, content and

focus of the exercises and discussions in the workshops.

1. *Organizations are unique* – each has an individual personality that is formed through the interactions between the people, systems, and contexts (or 'worlds') making up the organization. The individual personality, or self, of an organization will determine its response to the HIV epidemic.
2. *People are at the centre of the epidemic* – dealing with HIV/AIDS requires that we place individuals at the centre of our responses. At the same time we cannot forget that organizations have limited resources. Achieving a balance between the needs of the organization and the needs of staff members is critical.
3. *Policy-based approaches are limited in their application* – organizational culture (relationships and the way people and systems interact and construct each other) cannot be simply regulated. Policy can only be implemented effectively within the context of an open organizational culture.
4. *There is no single approach or generic solution for dealing with HIV/AIDS in the workplace* – solutions have to be crafted to suit the organization by the people who



Group work during a Leadership Forum meeting organized by Project Empower

work in that organization. Solutions to the problems that HIV and AIDS present are not permanent and have to be constantly reviewed and adapted in the light of new learning and experience.

5. *Organizations are not independent, isolated entities* – they operate within a fluid environment that impacts on their work, and the ways in which they work.

### Deriving lessons from practice

Policy development was seen to be one of a number of actions that needed to be ad-

ressed in developing a comprehensive workplace programme. Workplace programmes should include activities to reduce stigma and create a more open and accepting organizational culture; the provision of treatment and care; prevention; and psychosocial support. In addition, serious attention needs to be paid to work practices that place staff at risk of infection. The primary consideration though in designing a workplace programme – and all its components – has to be realistic and take both resource constraints and the culture of the organization into consideration.

While much time was devoted to building a clearer understanding of the impact of HIV/AIDS, participants in the pilot felt that it was essential that lessons from implementation be shared and discussed in the group and that the future process should focus on implementation and deriving lessons from practice. It was felt that it was important that the group met a considerable number of times and that efforts be made to support each others' programmes – in terms of skills, resources and learning opportunities. Another lesson was that donor organizations are critical in the process of finding solutions and should be more intimately involved in the programme (see Box on p.13).

### Building HIV-positive organizations

Based on the experiences of the first group, the programme 'Building HIV-positive organizations' was started in Spring 2005. It was designed to take into account the need for increased interaction and learning time, donor participation and creating opportunity for collective reflection. The 18-

### Lessons learned

- Lessons from the implementation of workplace programmes should be shared and discussed.
- Donor organizations can play a critical role in supporting programmes to deal with HIV/AIDS in the civil society workplace, and they need to be involved more intimately.
- Workplace policies can only be implemented effectively within the context of an open organizational culture.

month process will culminate in a learning event in September/October 2006.

The implementation of the programme relies on organizations' active participation in a Learning Group that meets regularly to share ideas, relate experiences of implementation and contribute to a collective pool of knowledge/learning. Learning groups are made up of 15-20 CSOs (both community-based and non-governmental) from a similar geographical region. Project Empower is working with two groups of organizations, based in the Eastern Cape and KwaZulu Natal Midlands. Participation in the learning group is limited to persons in the organizations who are in leadership positions – who are able to influence the organizations they represent.

Leaders from those organizations meet regularly over a year to examine the impact (current and predicted) of HIV/AIDS on CSOs' work broadly – and their organizations specifically. The main thrust of the workshop programme is:

- to build an understanding of the predicted



Symbol used by Project Empower to represent a non-profit organization: a nurturing womb that projects and nourishes the community but in a constant state of insecurity, having to balance a range of expectations

- impact and to relate that to their individual organizations,
- to develop individual workplace programmes to deal with the impacts,
  - to develop action plans and test responses in their organizations,
  - to participate in a peer support group to share their experiences and exchange advice and learning from implementation.

### Donor participation

In addition to the learning groups established for CSOs, interested donor organizations were invited to participate in a parallel, linked process to discuss strategies

to support the implementation of their partners' workplace programmes. The discussions in this learning group focus on the broader strategic implications for service delivery in the development sector and the role donor organizations can play in supporting programmes to deal with HIV/AIDS in the civil society workplace. Donor organizations will meet to examine and discuss recent research findings, and begin the process of developing a broader donor response to the predicted impact.

While donors have expressed significant interest in the idea, very few have actually

made a commitment to participate directly in the discussions, preferring to receive information from learning events.

### Sharing learning

Project Empower will facilitate the ongoing exchange of information and learning between all the participating organizations (donors and civil society organizations) and host a learning event at the end of the programme cycle. The goal of this event is to share lessons learned, evaluate the learning experience and propose a joint strategy for future work.

There is still much to be learned. This learning can only begin once we start implementing our plans – so that we can fail and adapt and modify what we are doing until we find solutions that are suitable for our organizations. We have to learn as individuals and individual organizations, but we also have to make sure that we are able to share our learning and learn from the trials and errors of others doing similar things. ■

### Donor roles

Do donors have a role to play in internal mainstreaming and NGO workplace programmes? Many international NGOs, like Oxfam, CARE International and VSO do have workplace policies and programmes for their own staff. Cordaid and Hivos have workplace programmes for their staff in regional offices. But what is the responsibility of a donor, while funding local NGOs?

A comparison: An HIV-positive person finds it difficult to be open about his/her status to the employer. If there is no written HIV/AIDS workplace policy, this staff member might risk career perspectives, less training opportunities, stigma, discrimination, etc. A written HIV/AIDS workplace policy gives staff the 'security' that it is safe to be open about HIV/AIDS and moreover the staff member is able to access the services as described in the workplace programme. The organization can give him/her and/or the family the necessary support (access to care, treatment, etc.)

The same is true for a director of a local NGO. The director finds it difficult to be open about the HIV/AIDS situation of his/her organization to the donor. Donors are keen to get concrete results from the local funded organizations. A local NGO that has difficulties in coping with HIV/AIDS and whose staff is heavily infected or affected by HIV/AIDS, does not function in an optimal way. Its results might seriously deteriorate. If there is no written donor guideline which explicitly acknowledges the impact of HIV/AIDS on counterparts and the policies of the donor in this regard, the director might fear he/she risks to lose further donor support.

This is the reason why Stop AIDS Now! (SAN!) has developed draft donor guidelines in order to be open and clear about donor's support to the implementation of workplace policies by local NGOs. SAN! is a partnership in the Netherlands between five organizations: one AIDS-focused organization (the Netherlands AIDS Fund) and four co-funding development agencies (NGO donors): Novib, Cordaid, ICCO and Hivos. SAN! started projects on HIV/AIDS internal mainstreaming and workplace programmes in four countries: Ethiopia, Sudan, Uganda and India.<sup>1</sup>

To curb the HIV/AIDS epidemic, NGO workplace programmes and donor guidelines are both needed to make the process of mainstreaming HIV/AIDS successful.

*Anny Peters, Novib and Stop AIDS Now!, e-mail: aids.kic@novib.nl*

1. The Ethiopia project is described on page 14.

### Allan Moolman

Coordinator Project Empower, Durban, South Africa

Correspondence:

Room 234 Diakonia Centre  
20 St Andrews Street, Durban 4001  
South Africa

tel: +27 31 3103565

fax: +27 31 3103566

e-mail: info@projectempower.org.za

# HIV/AIDS internal mainstreaming in Ethiopia

Some lessons learned of a first effort

Article produced as part of the KIC project

Carolien Aantjes & Lebesech Tsega

Photo: Kristoffer Walker



**Four Dutch development organizations (Novib, Cordaid, ICCO and Plan Netherlands), united in Stop AIDS Now! (SAN!), have initiated a joint venture aimed at supporting local NGOs in Ethiopia to mainstream HIV/AIDS internally. SAN chose Ethiopia because of the rapidly growing HIV/AIDS epidemic and seized the opportunity of using mainstreaming as an instrument to get an expanded multi-sectoral response to the problem. The first phase of the project was implemented from May 2004 until October 2005.**

During a workshop held in 2001 with Novib partners in Ethiopia, the participating organizations gave the impression that they were doing a lot for their personnel in raising awareness and could not see the need for internal mainstreaming and policy guidelines. Though some organizations were undertaking activities to decrease the stigma around HIV/AIDS in the communities in which they worked, the silence and the stigma associated with HIV/AIDS were very high in their own organizations. A few organizations had already lost some employees to AIDS by then.

The importance of HIV/AIDS internal mainstreaming was better recognized during a discussion carried out in 2003 between Novib and several organizations, including those who participated in the previous workshop. The partners expressed the dilemma they faced in helping and serving their communities and educating the public when they were themselves not sufficiently equipped with the necessary capacities to respond to HIV/AIDS. Thus the partners showed their willingness to get help with mainstreaming HIV/AIDS internally. Subsequently, 14 partners of the four organizations were selected to participate in this project.

The overall goal of the project is to improve the capacity of local partners to deal with the effects of HIV/AIDS at the organizational level. The main tool used is the 'Framework for Organizational Diagnoses on HIV/AIDS Competency', also known as 'the 12 Box Model', which assists organizations in mainstreaming HIV/AIDS (see Box). This framework, developed by Novib, can be used in a self-assessment workshop to identify strengths and weaknesses of an organization with regards to internal mainstreaming. The framework was pre-tested in Ethiopia with several Novib counterparts.

## Self-assessments

In May 2004, a preliminary workshop was conducted with all the 14 organizations to introduce the project. Afterwards, tailor-made self-assessment workshops were facilitated based on the 12 Box Model. The management, senior and junior staff participated in these workshops conducted by individual organizations. Eleven of the 14 organizations carried out individual self-assessment workshops; the other three organizations did not continue with the self-assessment and the rest of the process for various reasons.

Based on the results of the workshops, each organization developed an action plan.

Planned activities ranged from training needs assessments, staff awareness sessions, experience-sharing visits to peer organizations, making condoms available in the office, offering VCT services to staff, developing HIV/AIDS policies and mainstreaming guidelines, adapting other organizational guidelines like staff manuals and job descriptions, to preparing proposals to donors for future funding.

The participating NGOs appointed focal persons or committees, both at head office and field office level, who are responsible for the overall coordination of the activities. In the implementation phase, all NGOs made use of external consultants or resource persons to assist them in the development of organizational policies or facilitating staff training. There was a strong emphasis on the input from staff during policy development.

## Lessons learned

The following reflections and lessons could be drawn from the participating NGOs:

- NGOs reported that their staff was eager to have a workplace policy. One of the NGO directors felt that a policy would be an important tool to retain staff within the organization.
- The fear of stigma and discrimination challenges the NGOs in this process. "Even when educated you don't feel comfortable disclosing; you fear discrimination. In the absence of a workplace policy, I would rather buy my own medicine than disclosing my situation to the organization" (focal person).
- Some NGOs reported resistance from

### The 12 Box Model

The 12 Box Model helps in getting insight into the HIV/AIDS competency of organizations and understanding their strengths and weaknesses regarding HIV/AIDS mainstreaming. It was adapted from a gender-mainstreaming model, and based on experiences of gender mainstreaming. This model had originally three key organizational elements: 1) vision and mission, 2) organizational structure and systems, and 3) human resources. An additional dimension, i.e. programme policy and practice, was added during the adaptation, in order to include the analysis of external mainstreaming. The framework guides the assessment of HIV/AIDS competence of organizations from governance, technical and cultural points of view in a systematic way.

In using the framework, organizations reflect on their practice using checklists (concrete questions) prepared on each of the 12 boxes. The assessment is better done in group discussions and with the participation of all staff. Commitment and full participation of management is crucial. The process helps identify the strengths and weaknesses of organizations as well as opportunities and threats, and leads to the prioritization of immediate problems that organizations want to respond to based on subsequent action plans.

Currently, Novib is refining the 12 Box Model.<sup>1</sup>

		Key organizational elements			
		I. Vision/mission	II. Organizational structure	III. Programme policy and practices	IV. Human Resources
Viewpoints	Governance (political)	Decision-making on HIV/AIDS	Decision on internal HIV/AIDS policy	Decision on HIV/AIDS mainstreaming in programmes	Human resource planning
	Technical	Incorporation of HIV/AIDS issues in vision/mission	Tasks and responsibilities	Programmatic issues including monitoring and evaluation	Staff and expertise
	Cultural	Cooperation and learning	Organizational culture (communications, relations, etc.)	Approach, attitude towards target group (participatory)	Attitude of staff

### Lessons learned

- A self-assessment provides NGOs with a good head start/insight into basic issues that internal mainstreaming should address.
- It helps them to identify present strengths and weaknesses in their internal response to HIV/AIDS and the subsequent action that is needed.
- In planning, they need to carefully consider issues like staff acceptability and involvement as well as embedding internal mainstreaming activities in their organizational structures to ensure sustainability.

staff: some members of staff were tired of hearing about HIV/AIDS; others resisted the idea of having condoms at the workplace or going for VCT. Others were positive after going through the exercise. "I thought the training was going to be boring, thinking I knew all about HIV/AIDS but I actually learned new things and found the training very interesting" (focal person).

- NGOs organized regular open dialogue sessions or social events to break the silence on HIV/AIDS and strengthen mutual relationships. A number of NGOs reported that staff became more open in discussing

HIV/AIDS issues, something that is not all too common in the Ethiopian culture. "I told you that my aunt was sick. That is a very shameful thing according to our Ethiopian culture; I am now ready to help the HIV patients, in any case, even if I am asked to contribute a part of my salary I am not retreating" (finance manager).

- Two NGOs that had included the option for VCT in their action plan, reported that already some of their staff had taken this up. In one NGO that had its own VCT provision, six out of a total of 31 staff members went for testing. The organization had also offered to pay for testing elsewhere if staff did not want to be tested in their own clinic, but nobody had opted for this. In another NGO, three out of the 59 staff members were tested.

### Scaling up

The lessons learned as well as the follow-up were discussed in October 2005. The joint project now enters Phase 2 and the project will be scaled up to other NGO partners in Ethiopia, with the assistance of an NGO whose core business is organizational capacity building. More clarity on funding internal mainstreaming processes is expected to come from the donor guidelines that are currently being formulated.

Despite the fact that toolkits on internal mainstreaming are available, the Ethiopian NGOs expressed the need to learn through practical experiences. However, few experiences have been officially documented. The experiences in Ethiopia have therefore been documented and published on 1 December 2005 (World AIDS Day) to promote linkages and learning, especially among national/indigenous NGOs.<sup>1</sup> ■

### Carolien Aantjes and Lebesech Tsega

Independent consultants in respectively the Netherlands and Ethiopia. The authors wrote this article on behalf of the Joint SAN Project in Ethiopia. Carolien Aantjes was the project coordinator during the first phase of the project; Lebesech Tsega implemented the project in Ethiopia and facilitated the self-assessment workshops.

Correspondence:

Carolien Aantjes

e-mail: carolien.aantjes@wanadoo.nl

1. For more information on this model, the project and its follow-up, please e-mail: aids.kic@novib.nl

# Being HIV positive in an ‘HIV-positive’ organization

**The experiences of Rose, a woman living with HIV in Zimbabwe**



*Article produced as part of the KIC project*

**My case can be described as being in the right place at the right time. I was looking for a job and saw an advertisement, which stated at the bottom: “HIV-positive people are encouraged to apply.” I had applied for employment in the private sector previously and I had been made to undergo HIV testing without my consent, under the excuse that blood counts were necessary for ‘medical examinations’ which would determine whether one qualifies for a job or not.**

When I came to my current organization for a job interview I disclosed my HIV status and therefore from the first day at the organization the Executive Director and senior management knew about my status. At that time there was no internal HIV/AIDS policy in the organization and ARVs were not affordable at all in Zimbabwe. ARVs would cost about 100 GBP per month (US\$ 180) and my salary was about half of that amount. A good physician at that time encouraged me not to start treatment but take care of my diet and learn more about HIV. At that time, i.e. in 2002, I had been living with the virus for nine years.

In 2003, the organization came up with a workplace policy. At that time the policy was not very clear regarding treatment. For instance, should a time arise when someone needed treatment, were his or her dependents also covered? Were this to be so, then a lot of money would be involved considering how expensive ARVs were, and this required 100% commitment from the employer.

When the workplace policy was introduced, there had been two cases of staff deaths due to AIDS-related ailments – but they did not disclose or disclosed too late and not much could be done by the organization to help them.

## Learning about medication

Luckily I managed to stay without treatment until August 2004 when generic drugs started coming onto the Zimbabwean market and some medical aid companies now offered an add-on to their normal

policies to cover HIV/AIDS. Our organization paid for the add-on package for all staff. This implied that I could access ARVs and lab testing for as little as US\$ 4. Management of HIV (CD4 count and viral load testing) and medication are covered under this arrangement.

Furthermore, my organization set up a pool of funds, which is used in case any staff needs treatment. A special taskforce of committed employees plan workplace activities and do a lot of fundraising to implement them. With the money from the fundraising activities, I

**“Having that policy written down, in black and white, made me feel secure”**

can pay my physician’s consultation fees. When I need something else, it is easier to ask for assistance because I have disclosed. I just go to my boss and talk about it. When I started treatment last year, I took 10 days sick leave to adjust to the medication. That was no problem at all. I am happy to say that in August 2005 (after one year of treatment) my CD4 count was 460 and my viral load is now undetectable.

Every time I go for a test I give my boss an update on how I am doing. And now with increased treatment literacy at my workplace, I am learning more and more about the medicines. I have all the resources here at hand in the resource centre, so I can look up anything I need to know about. I feel lucky because I have all this information available.

## Safe and secure

Let me take you back to when I joined my current organization. Seeing that advert, applying for that job and starting with that workplace programme made me feel safe. I knew that when I needed treatment, I would most likely receive help from my organization.

Having that policy written down, in black and white, made me feel secure. Not only did I disclose to more colleagues than before, I also opened up to many family members. They are now more knowledgeable about HIV/AIDS than before. Now, I often give lectures about HIV/AIDS-related stigma and discrimination, drawing from my own experiences.

By opening up to community members and school children about my HIV status, and showing that people like me can look perfectly healthy, I hope to reduce some of the stigma and discrimination which are still prevalent. I have also disclosed to some very close friends. People who go through denial after they have learned that they are HIV positive sometimes come to talk to me. I am like a mentor for some of them. Also, I have my own support group of five or six friends who are HIV positive. We do things together and support one another when one of us is ill.

I feel much safer now than before. Even when the Zimbabwean economy is not doing well, I am not afraid of losing my job. If I need to go to the lab for my test results, or get new supplies of medicine, I can go there, even during working hours, without fear of being dismissed. I get a lot of support from my boss and colleagues. Most people here know I am HIV positive and they are very supportive. ■



Photo: WHO/UNAIDS/Sven Torfinn

### Rose (not her real name)

is working in an HIV/AIDS organization in Zimbabwe

Correspondence:

Rose, c/o the editor of *Exchange*

e-mail: [exchange@kit.nl](mailto:exchange@kit.nl)

## Resources on internal mainstreaming

### Building organisational resilience to HIV/AIDS:

*Implications for capacity building*

R. James, Praxis Paper 4, INTRAC, 2005 (40 p.)



This paper highlights the vital role of capacity building providers in ensuring that organizational resilience to HIV/AIDS is brought onto the agenda of their clients. This is especially important because many CSOs may feel overwhelmed by the possible impacts of HIV/AIDS on their own organization. Capacity builders need to be very aware of the issues and have the competencies to support clients in addressing HIV/AIDS mainstreaming in their external programmes and relationships as well as in their internal organization.

[www.intrac.org/pages/PraxisPaper4.html](http://www.intrac.org/pages/PraxisPaper4.html) (English and French),  
hardcopy: [www.intrac.org](http://www.intrac.org) (£5.95)

### HIV/AIDS mainstreaming:

*A definition, some experiences and strategies. A resource developed by HIV/AIDS focal points from government sectors and those that have been working on HIV/AIDS mainstreaming*

H. Elsey & P. Kutengule, HIV/AIDS/STI Knowledge Programme, HEARD, 2003 (59 p.)

[www.sarpn.org.za/documents/d0000271/P263\\_HIV\\_Report.pdf](http://www.sarpn.org.za/documents/d0000271/P263_HIV_Report.pdf)

### Taking responsibility. Why, for whom and how?

*Report of a study of HIV & AIDS workplace policies among and for Share-Net member organisations*

W. Koster, Share-Net, 2005 (42 p.)

[www.share-net.nl/assets/images/HRM\\_and\\_AIDS\\_study\\_report.pdf](http://www.share-net.nl/assets/images/HRM_and_AIDS_study_report.pdf)

### Implementing the ILO Code of Practice on HIV/AIDS and the world of work: an education and training manual

ILO Programme on HIV/AIDS and the World of Work, 2002 (329 p.)

[www.ilo.org/public/english/protection/trav/aids/publ/manual.htm](http://www.ilo.org/public/english/protection/trav/aids/publ/manual.htm)  
(available in English, French and Spanish)



## Soul City, South Africa:

### Partnering with the media and civil society in achieving social change

*Shereen Usdin*

**In 1996, an article was published in *AIDS/STD Health Promotion Exchange*, a predecessor of *Exchange*, on the new multimedia programme Soul City.<sup>1</sup> The programme was started in late 1992 and comprised a package of radio, television and educational materials with the aim of getting health promotion information to the widest possible audience. The project identified disadvantaged black South Africans – especially young women in lower income groups – as the primary target audience.**

A year-long consultative research process was undertaken to ensure that materials were of the highest standard. Focus groups of target communities pre-viewed pilots of the first radio and TV episodes. The scripts had to be true to life and educate, yet contain enough dramatic elements to keep the viewers' attention.

Soul City at the time comprised of:

- Television: a weekly half-hour drama series aired during prime time. The series used the drama format to produce 'edutainment' – entertainment with an empowering health promotion message.
- Radio: a 15-minute daily serial aired in Zulu, Xhosa and Sotho languages on South Africa's three largest radio stations.
- Newspapers: a 36-page, full-colour booklet was serialized in the major newspapers over three months; 600,000 booklets were distributed in the newspapers. Additional copies were distributed by clinics and at petrol stations countrywide.
- A public relations and advertising campaign: developing editorials, competitions, and a range of actuality programmes to popularize the series and to use the actors as advocates, placing health issues on the public agenda.

- An education package: using audio, video and written materials adapted from the mass media, for formal and informal educational settings.

### Expansion and consolidation

The programme concentrated on: safe motherhood, breastfeeding, infant nutrition, diarrhoea, respiratory disease, child abuse and accidents. Other sub-themes integrated into the stories included community and women's empowerment, stigma, social issues such as co-parenting, community action, nation building, and, last but not least, communication about sexuality and HIV/AIDS awareness (see Box).

Since then, Soul City has developed into the Soul City: Institute for Health and Development Communication (SC: IHDC). It has won a range of awards locally and internationally for 'best practice' and innovation. The organization has expanded the scope of its work to include *Soul Buddyz*, a multi-media initiative aimed at 8-12 year olds and their caregivers. Soul Buddyz consists of a television drama coupled with a radio programme and print material for children and caregivers. A national network of Soul Buddyz Clubs have been established at schools and libraries across South Africa to build on the health promotion work of the Soul Buddyz multi-media vehicle. The clubs encourage community activism amongst young children and are for children by children. More recently, a television programme called *Buddyz on the Move* has been developed as an inspirational tool, to showcase the work of clubs.

### The key to success

The two vehicles have huge reach with Soul City reaching 79% of the South African population and Soul Buddyz reaching 68% of children. Independent studies cite greater brand knowledge of Soul City when com-



pared to Coca Cola.<sup>2</sup> Soul City has produced seven series so far and Soul Buddyz is now in its third. Numerous evaluations have demonstrated significant impact in terms of social change.<sup>2</sup> Previously disadvantaged black South Africans are still the main target audience of Soul City but it has been expanded by including a greater representation of diversity in the characters. Soul Buddyz is aimed at all children and caregivers regardless of ethnicity or socio-economic background.

The life-skills materials are used in schools and the educational packages, adapted from the television series, are distributed widely within the country. Fifteen NGOs have been trained as master trainers and, using a cascade model, train others to use the educational packages.

### **Avoiding ‘Soul City/Buddyz fatigue’**

We believe that the key to our success is rigorous formative research that ensures our materials resonate with our audiences and have the desired impact. People speak of our series mirroring their lives. Also, our constant evaluations ensure that we learn important lessons, which are applied to the development of the next series. The careful building and marketing of the Soul City brand as well as strategic use of popular actors has also helped in our success. We have always relied on a ‘win-win’ strategy, which balances the benefits for the programme with those for the broadcasting corporations. This has allowed us to bring in massive audiences and helped the broadcaster fulfil its public broadcasting mandate.

### **HIV/AIDS and sexuality messages**

Over the years messages on HIV/AIDS prevention, care, treatment, support and related issues such as sexuality and sexual decision-making have been included in the Soul City series and materials. Some of these messages are that with antiretroviral treatment, HIV/AIDS is a chronic disease, no longer a death sentence; you cannot know you are HIV negative unless you are tested; responsible partners support and care for each other; you can benefit from disclosure; have an HIV test if you want to have a baby; ART is not a cure but it makes HIV a manageable condition like hypertension or diabetes, etc.

Further, Soul City pays a lot of attention on gender inequality and promotes the norm that men and women are equal and have the right to make their own choices around sex; young men can control their sexual urges and this will not have negative physical or psychological consequences (directly addressing a common misconception); love does not equal sex or material goods; forced sex is rape, even if it is your boyfriend, etc. Masculinity messages promoting men as carers and the notion that “you can be a different man from peer expectations” are also addressed.

Young people often experience these messages as eye-openers, as one young female respondent stated in the evaluation of the fourth series: “It [Soul City] made me to know where I stand as an individual. It was able to show me what is wrong and what is right, and it made me to be able to determine where my life is going and what path am I choosing for myself....It has taught me that I should not depend on a man, I should learn to stand on my own, and that I should think for myself, and again I should respect other people... I have rights”.

A young man said: “Me and my friends had a style of changing girl friends to surprise each other. I will bring this girl today and tomorrow a different one – telling ourselves that AIDS has its own people. And we did not use condoms. After watching Soul City with my friend, we realized that AIDS issues must be true... We got a shock and resolved to stick to one girlfriend and use a condom”.

Bearing in mind that research shows that children in the Soul Buddyz target age group have not yet begun experimenting with sex and drugs, issues of sexuality and HIV/AIDS are communicated differently from the way one may communicate with older youth. Thus far, Soul Buddyz messages have focussed on helping children to first understand their bodies and accept the feelings that come with the way their bodies change as they get older. Children are also encouraged to know that they have the right not to be touched in ways they do not like. They are also encouraged to identify their feelings and learn to deal with them appropriately, and not to feel ashamed of these feelings. Also Soul Buddyz does encourage measures that prevent pregnancy, HIV and STIs (such as safer sex). Children are encouraged first and foremost to delay sexual onset until they are older. In support of these messages, Soul Buddyz produces a parenting guide to help caregivers communicate messages of sex and sexuality with their children.

Beyond this, Soul Buddyz has also focused on different aspects of HIV/AIDS to raise awareness, dispel myths and convey information, looking at aspects of prevention, care, support and treatment. The series looks at how families, communities and schools can find ways to assist infected and affected children.

### Lessons learned from sustained practice

- Explore win-wins for both the programme and the media.
- Conduct rigorous formative research.
- Evaluate as appropriate.
- Explore multiple strategies to achieve social change.
- Build partnerships with media companies and civil society.



Over 10 years later, Soul City has repositioned itself to ensure it keeps pace with the changing media environment and an increasingly sophisticated media-literate population. The series itself looks quite different from its original form, while still maintaining the elements that have resulted in such an extensive 'brand loyalty.'

We are developing new projects continuously which build on the popularity of the Soul City brand. We are currently involved in a year-long talk show with all public broadcasting radio stations. These shows engage audiences interactively in the issues dealt with in the actual drama vehicles. We are also developing a reality television programme, which will encourage community transformation.

### International scaling up

Soul City has been broadcast in a number of countries throughout the world – as far afield as Surinam and Barbados. Between 1999-2001, Soul City worked on a successful project in Botswana, Lesotho, Swaziland and Namibia where a youth publication called *Choose Life*

was adapted for each country. Over 1,330,000 copies of the booklet were successfully distributed in the four countries in seven different languages.

The three-year process taught Soul City a lot about working regionally. Most valuable has been the lesson learned about the importance of working with good local partners who in turn root the programme within broader initiatives within the country and bring local credibility.

The current Regional Programme is a five-year programme, which seeks to develop media and build local capacity by working with identified partners in eight other sub-Saharan countries. The regional partners are: PSI (Botswana and Malawi), Phela Health and Development Communications (Lesotho), Vida Positiva (Mozambique), Namibian Red Cross Society, Schools Health and Population Programmes (SHAPE, Swaziland), Zambia Centre for Communication Programmes (ZCCP), and Action Magazine (Zimbabwe). The two main aims of the programme are to adapt Soul City media – TV, radio and print – in each of the countries and build local capacity.

The 1996 article stated that the producers hoped that the series would come to rely less heavily on donors. While we do receive substantial commercial sponsorship as well as airtime arrangements with the public broadcaster, we still rely in large part on donor funding, due to the magnitude of our work. We are currently however, exploring other longer-term sustainability options. ■

### Shereen Usdin

Senior Manager, Soul City Institute for Health and Development Communication, South Africa

#### Correspondence:

PO Box 1290, Houghton, 2041 South Africa

tel: +27 11 6435852, cell: +27 73 2153763

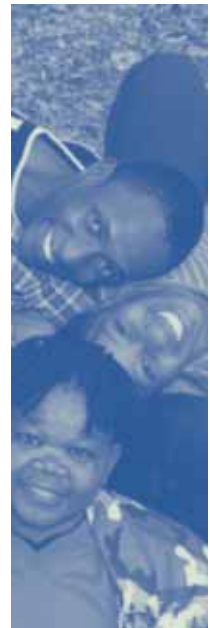
fax: +27 11 6436253

e-mail: shereenu@soulcity.org.za

web: www.soulcity.org.za

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# Claims and realities in HIV programme evaluation



Condom demonstration by youth group at Soweto Youth Centre, South Africa  
Photo: UNAIDS/Pirozzi

## The example of loveLife in South Africa

Warren Parker

**HIV/AIDS interventions face particular challenges in meeting funding goals on the one hand, and proving impacts on the other. In some instances this may result in approaches where evaluation methods and findings are insufficiently critical. One such example can be found in the research approaches and claims made by the loveLife programme in South Africa.**

Launched in 1999, loveLife had ambitious goals as an HIV prevention programme targeting South Africa's youth – one being to “reduce the incidence of HIV among 15 to 20-year olds by 50 percent over the next three to five years.” This goal was framed alongside a model of large-scale and multi-faceted national intervention that would tap into youth aspirations through an intervention of unprecedented scale, with an annual budget requirement of around R200 million (\$31 million).

Investment in this programme was led by loveLife's founding funders, the US-based Henry J. Kaiser Family Foundation, which drew on endorsements from politicians, business and media elites in South Africa, and numerous individuals and organizations globally, to acquire additional funding support. The goals of the programme were framed against an evaluation plan that included regular monitoring and regular reporting of findings.

The challenge for the loveLife programme was two-fold. The first was to demonstrate rapid results and impacts, and the second, to demonstrate that loveLife was the single causal factor that brought about such changes. Apart from the national antenatal

prevalence surveys, no baseline data was available against which the claim to ‘incidence’ reduction was to be measured. Instead, evaluation during the first three years was conducted through monitoring of programme activities, small-scale qualitative research and ‘national’ surveys.

### Claims to impact

In the early phases, findings were used to suggest generalizable national impacts even though sample sizes were small. For example, based on a number of small scale studies, a 2001 summary of evaluation findings stated: “In just under 12 months loveLife has succeeded in creating national recognition among close to 60% of the

Research findings are often accepted at face value, and when repeated in the media, in brochures, reports and websites, they have the capacity to appear rigorously grounded and ‘true’

population” and that “loveLife has had a remarkably balanced impact across age groups and regions.”<sup>1</sup> Sample sizes for the studies from which these conclusions were drawn were small (1000 in one and 141 in another) and sampling methodologies were not presented in detail.

Claims to early impact were soon reinforced by a follow-up study reported in 2002 of youth aged 12-17 – loveLife's primary target group – which suggested that loveLife had an impressive ability to socially engineer youth response to HIV prevention. Findings included:

- Of all young South Africans, 62% know about loveLife.
- Of those who know about loveLife, 76% say loveLife has made them more aware of the risks of unprotected sex; 65% say loveLife caused them to delay or abstain from sex.
- Among sexually experienced youth who know about loveLife, 78% say loveLife has caused them to use a condom; 69% have reduced their number of sexual partners; 63% say they are more assertive in insisting on condom use.<sup>2</sup>

Whilst experienced researchers and evaluators would immediately note the problems

and limitations of using leading questions to derive such findings, the results were directed towards wider audiences beyond the research community. The study report itself carried these findings on the cover, and findings were also repeated under the headline ‘HIV prevention that works’ in



various versions of the organization's promotional brochure. Findings were also widely promoted in the media, in a number of reports related to HIV/AIDS and on

When findings are presented in ways that circumvent peer review and commentary by other researchers in the field, they are able to avoid or limit critique

various websites. In 2004, the results were also integrated into the cover design of loveLife's promotional brochure.

### HIV prevalence rates

Such claims about making significant impacts did not correlate with HIV prevalence rates amongst youth as reflected in ante-natal studies, where numbers were not declining (let alone being reduced by half). In 2000, the level for pregnant females under 20 was 16.1%. With minor fluctuations it was, once more, 16.1% in 2004. National population-based surveys have also shown high rates of prevalence amongst youth – one in twenty 15-19 year-olds were found to be HIV positive in 2003 in a survey conducted by the Reproductive Health Research Unit (RHRU) – a loveLife partner organization.<sup>3</sup>

The lack of progress in relation to HIV prevention has been subtly moderated in loveLife promotional material over time. In 2002 the organization's brochure framed the goal as "to cut the infection rate amongst young South Africans by 50 percent," without reference to the initial three to five year timeframe, and in 2003 the goal was restated as "to substantially reduce the

infection rate" without reference to the goal of 50 percent HIV reduction. The programme's timeframe for impacting on HIV has also been shifted. In mid-2005 loveLife's website stated the programme was "now in its fifth year... in the middle of what was originally designed

as a 10 year campaign." Claims to impact have continued to be made, including, for example, most recently, that loveLife has a 'protective effect' for HIV prevention – a claim that is insufficiently substantiated.

### Implications

HIV prevention is a complex process and it is impossible to absolutely measure the impacts of specific HIV prevention interventions. This poses problems for programme evaluation. Programme funders and implementers are often closely involved in the design of monitoring and evaluation systems, and findings that suggest impacts are useful to securing ongoing funding. It therefore requires considerable discipline and critical capacity to ensure that findings are not skewed to support these long-term goals.

Research findings, particularly quantitative findings, are often accepted at face value, and when repeated in the media, in brochures, reports and websites, they have the capacity to appear rigorously grounded and 'true.' When they are presented in ways that circumvent peer review and commentary by other researchers in the field, they are able to avoid or limit critique. Additionally, when findings are promoted internationally, they are well beyond the critical voice of local researchers and others who may be aware of the programme's limitations.

In the initial phases of the loveLife programme, claims to high levels of impact helped to foster buy-in amongst political, media and corporate elites in South Africa – many of whom are represented on the programme's local advisory board. Internationally, the programme has been presented as an effective model for HIV

prevention, and the research claims above have been widely repeated in conferences and reports. The claims also formed part of the programme's proposal to the Global Fund for HIV/AIDS, TB and Malaria – eliciting an initial commitment of \$12 million, and with a further \$56 million currently under review.

The research claims outlined here, along with many others made by loveLife, have made it difficult to understand what the programme's actual impacts might be. An approach based on critical evaluation would have value in that it would provide the capacity to adjust the intervention design as one proceeds – no model is perfect from the start. Claims that the model is working however, prevent any modification of design, and, in the case of loveLife, little has changed in the basic approach of the programme. In the short-term, claims about impact help to secure funding, and positive evaluation findings are no doubt pleasing to donors who make financial commitments. In the long-term however, this may breed cynicism of HIV prevention programmes as a whole. Ultimately, it's bad practice. ■

### Warren Parker

Director Centre for AIDS Development, Research and Evaluation (CADRE)  
Johannesburg, South Africa

#### Correspondence:

11th Floor, Braamfontein Centre  
23 Jorissen Street  
PO Box 30829, Braamfontein 2017  
Johannesburg, South Africa  
tel: +27 11 3392611, cell: +27 83 3784083, fax: +27 11 3392615  
e-mail: warren@cadre.org.za  
web: www.cadre.org.za

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Photo: Shunya, 2005

## Overcoming barriers to delivery of effective health services for fisherfolk

Janet Seeley & Edward Allison

**The mobility of fishermen and fish traders, long absences from home, cash incomes in the context of poverty, gender inequality, easy availability of commercial sex in ports and at landing stations, and a masculine culture that condones or encourages casual sexual encounters have been highlighted as increasing vulnerability to infection. These same life-style characteristics of fishermen also affect attitudes and access to treatment.**

A study in Thailand among 818 fishermen of Thai, Khmer and Burmese origin found that access to health care was difficult for fishermen not only while they were at sea, but also when they came on shore. Because of their mobility, they do not know what services are available in the places they stay. Difficulties in accessing health-care services were even greater for non-Thai fishermen, because of language and cultural barriers or their status as illegal workers in Thailand.<sup>1</sup>

Either as sex workers, girl-friends, partners or as wives, women in developing countries' fishing communities that have high HIV and AIDS prevalences are generally in a subordinate social position to men. This limits their ability, for example, to negotiate for the use of condoms for sex but also limits their access to treatment and care.

Access to HIV/AIDS testing and treatment facilities may be difficult for mobile populations. Mobility coupled with irregular working hours poses an even greater hindrance to adherence to treatment regimes. There is also a problem for poor patients who cannot afford the time off from wage-earning to attend appointments, particularly because of the long wait for treatment in busy health centres. A study in Uganda, for example, found that the distance from hospitals of the 21 fishing communities studied was up to 67 km and the journey could take up to six hours. A fisherman told the researchers: "I went to be tested but they said when I got there that it was the wrong day. I can't fish for another day, and I don't have 3000 shillings to go again."<sup>2</sup>

### Adherence concerns

Possible failure to take all doses of antiretroviral drugs is of concern because adherence to therapy is essential for successful management of HIV. The WHO guidelines, *Scaling up antiretroviral therapy in resource-limited settings* (2004), recommend treatment for people diagnosed with AIDS and people with HIV who have a CD4 cell count below 200. Because of concerns about the ability of health services to meet demand as well as ensure adherence, further criteria such as catchment area to define the population served and assessments of a person's ability to keep in regular contact with the antiretroviral therapy (ART) provider have been introduced in some places.

Criteria based on length of residence, a minimum of three months, and ability to keep booked appointments, were instituted because of the highly mobile nature of the population using the Médecins Sans Frontières (MSF) programme clinic in Khayelitsha (South Africa). In addition, the WHO guidelines suggest "continuous involvement of relatives, friends and/or community support personnel." People who are mobile cannot keep regular appointments, or fulfil residence

"I went to be tested but they said when I got there that it was the wrong day"

requirements and they do not always have family and community members on hand to provide support. The high degree of mobility among fisherfolk can affect the nature of the communities in which they reside. Mamadou Baro, for example, observes that in Uganda "fishing communities tend to lack any form of resilience to AIDS impacts due to the lack of community initiative to offer counselling, support or health care."<sup>3</sup>

Fishing may require being out at sea or on a lake for long periods of time, which means meals may be scanty and irregular, and keeping

### Missing out on 3 by 5?

- The WHO/UNAIDS '3 by 5 initiative' aims to provide life-long antiretroviral therapy to three million people living with HIV/AIDS in poor countries by the end of 2005.
- At the end of 2004 only 12% of the 5.8 million people currently needing treatment in developing and transitional countries had access to antiretroviral therapy. Even if the target of three million is reached by the end of 2005, that is still only half of those who need the therapy.
- Among the nearly three million 'left out' will be many mobile workers, like fisherfolk, because the same circumstances and activities that may put someone at risk of infection also affect people's access to treatment, care and support.

Source: *Impact of HIV/AIDS on fishing communities – Policies to support livelihoods, rural development and public health* (see Note 3)

to any form of medication schedule will be hard. While ART medications like Combivir and Nevirapine do not need to be taken with food it is recognised that without good nutrition people living with HIV/AIDS do not respond so well to drug treatment and may be prone to diseases like tuberculosis. So it is not only a matter of maintaining compliance in taking medications; a lifestyle that involves irregular meals and poor diet may impair the effectiveness of treatment. Consumption of alcohol, as a part of that diet, may also be problematic.

### Likely to be left out

For mobile workers, and remote rural communities, the inequities in access to services are a continuing fact of life. Issues of access to care and the mitigation of the impact of HIV/AIDS are just the latest among the challenges of making a livelihood for many such workers. For settled populations there have been recent successes in supplying ART in resource-poor settings. Well-known examples are the services provided by the HIV Equity Initiative in Haiti (see the article by Arachu Castro and Paul Farmer in this issue) and the Khayelitsha programme of MSF in South Africa. Considerable progress has been made in facilitating access to affordable treatment in sub-Saharan Africa and elsewhere. However, people with mobile livelihoods, such as fishermen, remain among those not only vulnerable to infection but also among those likely to be left out of the provision of care.

Long overlooked, the susceptibility of people in fishing communities to HIV infection and their vulnerability to AIDS-related illnesses is now being recognised and addressed. At global, regional and national levels, there is increasing recognition of the need to address HIV and AIDS among fisherfolk. The UN Food and Agriculture Organization (FAO) has recently produced a policy brief outlining the issue and suggesting ways to overcome the barriers to effective treatment and care outlined in this article.<sup>4</sup> The Asian Development Bank is funding HIV prevention initiatives among fisherfolk and seafarers in the Mekong River basin area.

The UK Department for International Development (DFID) supports the government of Gujarat (India) in targeting populations at risk (including fisherfolk) with access to condoms and sexual health services. Numerous NGOs, often working in partnership with fisherfolk's socio-professional organizations, are providing prevention advice and livelihoods support, such as the Médecins Sans Frontières programme in Zambia that trains men who are too ill to fish in less physically demanding tasks, such as tailoring. In Uganda, it is the fisherfolk themselves who have lobbied government for support in HIV/AIDS prevention and care. In Congo, community theatre has been used as a means to raise awareness about HIV/AIDS and to challenge existing norms of behaviour that make people vulnerable. With appropriate external support, fisherfolk are beginning to find their own solutions to the AIDS crisis. ■

*A more thorough discussion of the issues raised in this paper can be found in J. Seeley & E. Allison, HIV/AIDS in fishing communities: Challenges to delivering antiretroviral therapy to vulnerable groups. AIDS Care, 2005, 17 (6), p. 688-697: <http://taylorandfrancis.metapress.com> (free pdf, search on author)*

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#### Janet Seeley

Senior Lecturer, School of Development Studies, University of East Anglia, United Kingdom

#### Edward Allison

Senior Lecturer, School of Development Studies, and Sustainable Fisheries Livelihoods Programme, Food and Agriculture Organization

#### Correspondence:

Janet Seeley, School of Development Studies  
University of East Anglia  
Norwich NR4 7TJ, United Kingdom  
tel: +44 1603 592807, fax: +44 1603 451999  
e-mail: [J.Seeley@uea.ac.uk](mailto:J.Seeley@uea.ac.uk)



## Temporary migration and HIV vulnerability in China

Findings from a comparative research

*Xiushi Yang, Valerian Derlega & Huasong Luo*

**The link between migration and HIV has become a research issue worldwide. Recent studies in China have highlighted temporary migrants' vulnerability to HIV and STIs.<sup>1</sup> Particularly at risk are female migrants who become sex workers in China's flourishing entertainment industry.<sup>2-3</sup> There has been a phenomenal increase in the number of temporary migrants since the early 1980s. Millions of people migrate from rural areas to cities to look for better opportunities. Currently, up to 120 million temporary migrants are estimated to be living and working in cities. Unfortunately, many rural migrants are unprepared for life in the cities. This leads to psychological, social and behavioural problems that compel many to have multiple sexual relationships or end up as sex workers.**

The HIV epidemic is a ticking bomb in China. There were estimated to be about 840,000 people living with HIV and AIDS in 2003. According to a joint assessment by China's Ministry of Health and the UN Theme Group on HIV/AIDS in the country, the number of new HIV infections doubled or tripled from year to year in the early 1990s, growing by 44% on average yearly between 1994 and 2002. If the current trend is sustained, about 10 million people will be infected with HIV in China by 2010. Although the primary route of transmission is needle-sharing while injecting drugs, in coastal provinces and urban areas, sexual transmission is the main mode, accounting for more than one third of new HIV infections. There is considerable speculation that temporary migration, which involves no change in permanent residence registration, contributes to the spread of HIV in China.

Are temporary migrants really more likely than non-migrants to engage in risky behaviour that predisposes them to HIV? If they are, why? We conducted a population-based study comparing migrants directly

with non-migrants in risky drug use and sexual behaviours that could make people vulnerable to HIV. The study was funded by the US National Institute on Drug Abuse and covered an entire province in south-western China, a region that has been hard hit by the HIV epidemic.

We interviewed 3465 males and 2007 females who were a representative sample of the adult population in the province. Study participants completed a confidential questionnaire about their sexual and drug-using behaviours and were also asked about their personal experience of anti-social behaviour (e.g., "I have deliberately travelled on a train or bus without a ticket," "I have smashed, slashed, or damaged things in streets, cinemas, dance halls, trains, buses"). Indirectly, personal experience of anti-social behaviour indicates one's willingness to break social norms.

### Study results

A slight majority of the temporary migrants interviewed (58%) were male, averaged 29 years of age (30 for





Photo:  
Dominique Ganteille

male and 26 for female migrants), and 88% of them (85% of male and 91% of female migrants) received no more than a junior high school education. A majority of female migrants (63%) worked in the service and entertainment industries, while 61% of male migrants worked in factories, construction companies, or as self-employed. Almost a quarter of female temporary migrants self-reported commercial sex in the month prior to the survey, compared to only 5% of the male migrants.

Overall, we found that temporary migrants scored higher than non-migrants on every measure of illicit drug use and casual sex. Migrants also scored significantly higher than non-migrants on personal experiences of anti-social behaviour. Personal experience of anti-social behaviour turned out to be the most significant factor explaining migrants' greater likelihood of engaging in risky sexual and drug-using behaviour that could predispose them to HIV. In other words, being a migrant puts one in a situation in which she or he is likely to engage in risky behaviours and generally failing to adhere to social norms and values.

As many temporary migrants in China live and work in cities in the absence of their families, this separation /detachment can disrupt not only migrants' family life but also their sexual relationships. This is presumably encouraging casual sex and/or dependence on alcohol or drugs as a way to escape loneliness, to bury anxieties about work and family, and to address their sexual desires. The separation from family and home community can also create conditions in which many migrants feel less constrained by social norms since

family and friends back home are unlikely to discover what they do while away.

### **Socially isolated**

Furthermore, many rural-urban migrants are socially and culturally isolated from the 'mainstream' society in the city. They mostly live with fellow migrants at their place of work (such as construction sites) or at the city's fringes that may be characterized by lawlessness, overcrowding, and absence of social and health services. Being cut off socially from the mainstream society, migrants are deprived of exposure to role models and denied access to opportunities.

We found that respondents who were male and depressed were more likely to have HIV risk behaviours in the 30 days prior to the survey. However, the difference between migrants and non-migrants was more pronounced among females than males, suggesting that female temporary migrants experienced disproportionately higher increases in unprotected casual sex and HIV/STI risk after migration. There seems to be interaction between gender and migration, which renders female migrants particularly vulnerable. With little formal education and few job opportunities, female migrants are overwhelmingly (63% in our study) likely to seek employment in the service and entertainment industries, which increase their chances of becoming sex workers. As a result, economic hardships may lead female migrants not to bargain for safer sex.

Being a migrant seems to be synonymous with the risk of ever having an STI and/or being HIV positive,



### Lessons learned

- Temporary migrants who reported anti-social behaviour were more likely to engage in risky sexual and drug-using behaviours.
- Female migrants had more unprotected casual sex than non-migrant women.
- Being a migrant puts people in a situation in which they are likely to engage in risky behaviours and generally failing to adhere to social norms and values.

although there was no overwhelming evidence for this. It is unclear from the study whether self-reports in the survey may have underreported STIs and HIV infection. Because migrants have limited access to health services, including HIV/STI testing, this may contribute to underestimating STIs and HIV among migrants.



### Recommendations

In China, temporary migrants cannot obtain permanent residence registration in the host city, which excludes them from access to social and health services. Thus, many temporary migrants do not have equal access to socio-economic opportunities and HIV/STI testing or to educational programmes designed to tackle HIV. Lack of local residence registration and other rights is one of the main reasons why most temporary migrants leave their families behind. We found that this is the most important factor that contributes to migrants' psychosocial and behavioural problems, leading them to engage in risky sexual behaviour.

Hence, one important recommendation would be to encourage provinces in China to speed up household/residence registration reforms that will grant temporary migrants in cities equal access to social and health services. Reducing the barriers to equal access to resources in cities for migrants could help to reduce separation from family, promote assimilation and

integration in cities, reinforce normative influences of behaviour, and curb HIV risk behaviours.

Efforts should also be made to address gender inequalities in the urban labour market. Policies need to be reinstated to emphasize institutional support for gender equality in job training and hiring and to improve female migrants' access to the paid labour market. Meanwhile, government should rethink its policies on commercial sex. Criminalizing commercial sex by targeting female sex workers, who are mainly migrants, will further alienate them, limit their access to information and services, exacerbate power imbalances in commercial sex, and make them vulnerable to sexual and physical abuses by clients. Recent changes in regulations have reduced penalties for those caught in commercial sex. But it is time to de-link commercial sex from legal and economic punishments.

Finally, education programmes need to take into account the fact that many temporary migrants have no access to and are not entitled to government health care. Few have regular access to newspapers or TVs. Education campaigns delivered through the media will therefore have difficulty reaching temporary migrants. Those delivered through the government health-care system are also largely inaccessible to migrants. Urgently needed are education programmes that exclusively target temporary migrants. They should be integrated into job training and other services. ■

**Xiushi Yang & Valerian J. Derlega**

Old Dominion University, Norfolk, Virginia, USA

**Huasong Luo**

Yunnan Normal University, Kunming, China

Correspondence:

Xiushi Yang, Department of Sociology and Criminal Justice

Old Dominion University

Hampton Boulevard, Norfolk, Virginia 23529, USA

e-mail: xyang@odu.edu

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# In harm's way: How global abstinence-only and Global Gag Rule policies restrict sexuality around the world



International HIV/AIDS Alliance

*Stephan Tanbin Sastrawidjaja*

**Many reproductive and sexual health rights organizations have reported on the impact of anti-abortion and abstinence-only policies on women's reproductive health decisions. However, little is known on how these policies have affected men who have sex with men and other sexual minorities. In this article, the author shows how US-induced policies have led to a cut in vital funding support for sexual minority organizations, and asks for case studies from developing countries where the introduction of these policies have led to visible discrimination of sexual minorities.**

On the first day of George W. Bush's administration, the White House restored the Mexico City Policy, commonly known as the Global Gag Rule (GGR). The policy restricts non-governmental organizations funded through the United States Agency for International Development (USAID) family planning funds from using any monies, either from USAID or other sources, to perform legal abortions, provide information about abortions, or lobby their governments to reform abortion laws. Since his election to office, President Bush has increased the funding for global sexual abstinence-until-marriage programmes through the President's Emergency Plan for AIDS Relief (PEPFAR), created during President Clinton's administration in the 1990s, and re-launched on February 23, 2004. PEPFAR stresses the use of 'ABCs' of HIV prevention, that is, abstinence as a first choice, being faithful to one's partner and, as a last choice, consistent use of condoms.

ABC and GGR policies impinge on the rights of sexually active persons to access accurate and comprehensive information on the prevention of HIV and unwanted

pregnancy. These policies also harm marginalized groups like men who have sex with men (MSM), women who have sex with women, sexually-active HIV-positive persons, and sex workers, by placing them in stigmatizing 'high risk' categories. In the USA, the ABC policy in particular emphasizes abstinence as the only mode for the prevention of HIV/AIDS. When condom use is mentioned, the policy demands that programmes must underline that condoms are ineffective barriers to transmission, often with incorrect, grossly-exacerbated rates of failure.

In places where condom use is already culturally discouraged, publishing failure rates rather than promoting scientifically evidenced information that shows that condoms are the best and most effective measure for HIV prevention will only discourage the most marginalized groups from using them. In fact, because of these harmful demands and censorship of comprehensive and accurate information, many organizations on the ground will not disseminate information about condoms for fear of breaking USAID rules.

Many reproductive and sexual health rights organizations have recognized the impact of GGR on women's reproductive health decisions but little is said of how GGR has cut vital funding support for sexual minorities. For example, Young & Wise, one of the few MSM outreach groups in Ghana, can no longer distribute condoms because the supplier, USAID, can no longer give any to them. Young & Wise partner the Planned Parenthood Association of Ghana, which is affiliated to the International Planned Parenthood Federation (IPPF), has been blacklisted by USAID for supposedly providing information about abortions. By de facto, men who have sex with men are denied the full range of options needed to protect themselves from HIV infection.

**Many abstinence-until-marriage policies have actively biased interpretations of homosexuality**

## **Biased interpretations of homosexuality**

Many abstinence-until-marriage policies have actively promoted biased interpretations of homosexuality. In the USA, where the Bush administration has since 2000 spent more than US\$500 million on abstinence-only sex education, abstinence-only programmes have been restricted from providing sex education sensitive to the

needs of lesbian, gay, bisexual and transgender (LGBT) youth. In fact, these programmes, many of which are now being exported globally, promote a fear-based abstinence-only curriculum, which instructs that safer sex is only possible in the context of marriage. Programmes present extreme worst-case scenarios about sexually transmitted infections (STIs), exaggerate the failure rates of condoms, and foster stereotypes about gender and sexual differences. They often place responsible sexuality decisions on the shoulders of young women only. The programmes regularly omit discussion of sexual diversity.

Whenever these programmes refer to sexuality, they frequently conflate same-sex desire with STIs. For example, some federal-funded abstinence programmes in the USA have stated that half of LGBT youth are HIV positive. Since abstinence-only policies rely on a heterosexual concept of sex and family, they do not address sexual minorities such as gay men, who are forbidden to marry in most countries.

Furthermore, abstinence-only programmes have not been scientifically proven to be successful in delaying sexual initiation. In a study assessing the standards of evidence of 10 abstinence-only programmes, which claim to demonstrate actual delay of sexual debut and/or reduce teen pregnancy, all have failed to directly correlate abstinence with reduction in sexual activity and/or HIV transmission.<sup>1</sup> The review showed that young people who are only exposed to abstinence-only sex education become less willing to use condoms and contraception

once they engage in sex.<sup>2</sup> On the other hand, young people who receive comprehensive sexuality education become sexually active later, and are more likely to use contraception when they engage in sex.<sup>3</sup>

### Towards evidence-informed and rights-based policies

Men who have sex with men and other sexual minorities are frequently subjected to harassment, violence, discrimination and stigma within the family, at places of employment, in education and public life. These violations of human and sexual rights must be examined in the context of poverty, racism, sexism and homophobia. The USA is party to the International Covenant on Civil and Political Rights (ICCPR). It has also signed but not ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR). While it is not bound by the terms of the treaties, as a signatory, it has the obligation to refrain from actions that would defeat the treaties' object and purpose.

The GGR and ABC policies are not based on evidence but rather promoting ideology over science. They prevent access to comprehensive information that would help people make informed choices about safer sex. These policies present a need for advocacy and awareness on their effect on the rights of sexual minorities. One of the organizations taking up this challenge is the International Gay and Lesbian Human Rights Commission (IGLHRC), a US-based human rights organization. Some of the advocacy issues for developing countries are:

- The repeal of sodomy laws and other laws that criminalize same-sex relations.
- Adoption of legislation to protect the rights of PLWHA, including legislation to prohibit discrimination against them.
- Ensuring that the government and police monitor and regularly publicly report violence and abuse against persons at risk of or living with HIV/AIDS.
- Amending sexuality education to include scientifically accurate information concerning safer sex and condoms as methods of HIV prevention.
- Revising restrictions if applicable which do not permit health and educational

officials to provide information about HIV prevention, including information about appropriate use of condoms.

- Providing training on HIV, AIDS, sexuality and sexual diversity to all health officials, police officers, and those working in educational institutions. The training should cover, among others, the rights to privacy and protection of confidential information about HIV status.

IGLHRC is currently collecting case studies from developing countries where the introduction of abstinence-only or other US-induced policies have led to visible discrimination of sexual minorities. Together with other international partners, IGLHRC advocates for the modification of harmful US policies and urges governments of other countries to repeal discriminatory laws and put in place HIV/AIDS policies that are evidence-informed and rights-based. ■

*For reasons of space, most references have been removed.*

*Full references can be found in the web version of this article: [www.kit.nl/exchange](http://www.kit.nl/exchange)*

#### Stephan Tanbin Sastrawidjaja

Research and Policy Coordinator  
The International Gay and Lesbian Human Rights Commission, USA

#### Correspondence:

350th Ave, 34th Floor, New York  
NY 10118, USA  
tel: +1 212 2161278, fax: +1 212 2161814  
e-mail: [ssastrawidjaja@iglhc.org](mailto:ssastrawidjaja@iglhc.org)  
web: [www.iglhc.org](http://www.iglhc.org)

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Photo: Partners In Health/Jota Mukherjee, 2003



A community health worker delivering daily ARVs to a patient in rural Haiti

## The impact of comprehensive HIV/AIDS care on stigma and testing

Learnings and experiences from Haiti

*Arachu Castro & Paul Farmer*

**Haiti is by far the most impoverished country in Latin America and, not coincidentally, the region's most HIV-affected country, with an adult prevalence of around 6%. Since 1988, Zanmi Lasante – Partners In Health (PIH)'s sister organization in Haiti – has provided voluntary counselling and testing (VCT) for HIV free of charge to the population of the Central Plateau. Since 1998, in the framework of the HIV Equity Initiative, PIH has purchased antiretroviral drugs to treat patients living with HIV/AIDS, also free of charge. Preliminary data from research in rural Haiti suggest that the introduction of quality HIV care can lead to a rapid reduction in stigma, resulting in increased uptake of VCT.**

Supported by an already existing tuberculosis-control infrastructure, in 2001 we provided directly observed therapy (DOT) with antiretroviral therapy (ART) to about 60 patients with advanced HIV in and around Cange, a rural squatter settlement that hosts the Clinique Bon Sauveur, PIH's largest hospital in Haiti. By the end of 2005, our clinical staff will be following 7500 patients, of which 1800 are receiving ART. A group of over 900 community health workers – supervised by the clinical team – make daily visits to

patients at their homes to provide both the daily doses of ART and a range of associated support services. Of the HIV patients currently under treatment, the majority have achieved undetectable viral loads and they are able to live normal, active lives despite their chronic disease.

To illustrate how AIDS-related stigma is generated, we explored the history of one of our patients in rural Haiti:

*In 2001, Samuel Morin was dying of AIDS. Until then, Samuel, 40 years old, had farmed a small plot of land and had a tiny shop – which sold everything from matches to soap – in a town in central Haiti. He considered himself poor but was able to send his four children to school. Samuel was an active member of his church and sometimes used his meagre earnings to help neighbouring families in crisis, providing food if their crops failed, or helping with school fees. He also supported his sister and her three children after his brother-in-law died of AIDS.*

*When Samuel became ill in the mid-1990s, his wife had to assume all responsibility for the farming, although he could still sit and mind the shop. But after a while, Samuel recalled: "the disease transformed me. I looked like a stick." He continued to lose weight and then developed visible skin infections and thrush; he had difficulty swallowing food and began to cough. It was at this time that he felt that people stopped coming to his shop. His children had to leave school because they were needed to help in the fields and because Samuel and his wife could no longer afford the school fees. Eventually, the shop failed completely. His wife left him and returned to her parents' home in Port-au-Prince, Haiti's capital city.*

*In July 2001, when Samuel weighed only 80 pounds, he decided to use his last 10 Haitian dollars to pay for a truck ride to the Clinique Bon Sauveur in Cange. Since then, Samuel has been receiving free ART under the supervision of a community health*

For additional information on the programme in Haiti:

- A. Castro & P. Farmer, Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. *American Journal of Public Health*, 2005, 95 (1), p. 53-59
- P. Farmer, F. Léandre, J.S. Mukherjee, et al., Community-based approaches to HIV treatment in resource-poor settings. *Lancet*, 2001, 358 (9279), p. 404-409: [www.thelancet.com](http://www.thelancet.com) (free pdf, search on author name)
- *The PIH guide to the community-based treatment of HIV in resource-poor settings*. Partners In Health, 2004 (261 p.): [www.pih.org/library/aids/PIH\\_HIV\\_Handbook\\_Bangkok\\_edition.pdf](http://www.pih.org/library/aids/PIH_HIV_Handbook_Bangkok_edition.pdf)

worker. After three years of therapy, Samuel has not missed a dose; he has responded clinically, and has gained 30 pounds. He has normal skin colour, feels 'great,' and has an undetectable viral load.

Moreover, his family has returned to him, his children are back in school, and he has reopened his shop. He also volunteers with the local Partners In Health team in HIV-prevention efforts. Of his recovery, Samuel said: "I was a walking skeleton before I began therapy. I was afraid to go out of my house and no one would buy things from my shop. But now I am fine again. My wife has returned to me and now my children are not ashamed to be seen with me. I can work again."

### Lessons learned

- The introduction of antiretrovirals has had a positive impact on the demand for VCT.
- Improving clinical services can raise the quality of prevention efforts, boost staff morale, and reduce AIDS-related stigma.
- Social services must be part of a comprehensive project, as must attention to tuberculosis and primary health care needs.

In reflecting on Samuel's experience, it is possible to argue that AIDS treatment can start a 'virtuous social cycle.' Access to comprehensive AIDS care saved Samuel's life; returning to work and securing school fees for his children has allowed him to surmount some of the miserable conditions faced by the majority of Haitians. There are the links mentioned by Samuel: proper HIV/AIDS care can transform a disfiguring and consumptive disease into a manageable condition that is invisible to others.

Integrating people living with HIV into the workforce of a community health programme – at least 5% of our current staff are persons living with HIV – permits them to earn steady wages and send their children to school. Further, the demonstrably favourable response of Samuel and others to antiretroviral treatment has sparked interest in VCT. Together, these processes have contributed to lessening the impact of the AIDS stigma.

### Impact on VCT

The Haiti project already demonstrates that individuals who can access effective care are the most likely to get an HIV test. The introduction of antiretrovirals has had a positive impact on the demand for VCT. Since 1998, when we introduced the first free and comprehensive AIDS programme in rural Haiti at the Clinique Bon Sauveur, demand for such services has grown exponentially.

Samuel Morin was diagnosed and treated initially in Cange. But looking at his hometown of Thomonde, where community-based AIDS care was introduced only in 2003, is instructive. Our preliminary data suggest that VCT may increase rapidly when

comprehensive prevention and care are introduced. In Thomonde, VCT sessions per month have skyrocketed from 0 to an average of 870 in the second quarter and up to 1450 in the fourth quarter; at the Clinique Bon Sauveur, the number of VCT sessions are stable, averaging 2120 per month.

### Comprehensive services

As so many of our patients have noted, there is no motivation for learning one's serostatus when there is no possibility of being treated for opportunistic infections or of access to prevention of mother-to-child transmission during pregnancy. Much less so if there is no possibility of being treated with antiretrovirals when needed. Can we blame these public health failures on stigma alone? The Haiti experience suggests that improving clinical services can raise the quality of prevention efforts, boost staff morale, and reduce AIDS-related stigma. Our team's experience suggests that the full participation of community health workers will be required if HIV prevention and care are to reach the poorest and most vulnerable communities. Social services must also be part of a comprehensive project, as must attention to tuberculosis and primary health care needs.

The transformation of AIDS from an inevitably fatal disease to a chronic and manageable one has decreased stigma dramatically in Haiti, as Samuel's story shows. Our own experience in Haiti suggests that it is clear that the impact of a 'low-tech' HIV prevention-and-care project could be measured without importing a new and costly evaluation infrastructure. The most daunting challenges for which scale-up projects must be prepared are those having to do with the poverty of patients. ■

#### Arachu Castro

Assistant Professor of Social Medicine  
Department of Social Medicine (Harvard Medical School)

#### Paul Farmer

Professor of Medical Anthropology  
Department of Social Medicine (Harvard Medical School)

Both authors are involved in Partners In Health and in the Division of Social Medicine and Health Inequalities Brigham and Women's Hospital in Boston.

#### Correspondence:

Arachu Castro, Program in Infectious Disease and Social Change, Department of Social Medicine, Harvard Medical School / Partners In Health  
641 Huntington Avenue, Boston, MA 02115, USA  
tel: +1 617 4326038, fax: +1 617 4326045  
e-mail: arachu\_castro@hms.harvard.edu  
web: www.pih.org

## → Manuals & Guidelines

**HIV counseling and testing for youth: A manual for providers.** YouthNet/Family Health International, 2005 (92 p.)  
Pdf: [www.fhi.org/en/Youth/YouthNet/rhrtrainmat/vctmanual.htm](http://www.fhi.org/en/Youth/YouthNet/rhrtrainmat/vctmanual.htm)  
Hardcopy: [youthnetpubs@fhi.org](mailto:youthnetpubs@fhi.org)



With this booklet, service providers and counsellors can improve their counselling skills and assist youth better. The manual provides step-by-step information for using the traditional VCT model with youth and a special counselling and testing model for youth in clinical settings. It also offers resources, information, tips, guidelines and role-plays, etc.

**Synergising HIV/AIDS and sexual and reproductive health and rights. A manual for NGOs.** Aidsnet & WHO/Europe, 2005 (63 p.)  
Pdf: [www.manual.aidsnet.dk](http://www.manual.aidsnet.dk)  
CD-Rom and/or hardcopy: [aidsnet@aidsnet.dk](mailto:aidsnet@aidsnet.dk)

This manual provides practical guidance to NGOs working in low-income countries by addressing issues such as mainstreaming HIV/AIDS, sexual and reproductive health and rights; gender; the rights-based approach; sexual minorities and same-sex sexual activities; abortion and post-abortion care; and district health planning. The CD-Rom contains a pdf of the manual as well as other resources.

**Ethical approaches to gathering information from children and adolescents in international settings: guidelines and resources.** K. Schenk & J. Williamson, Horizons/Population Council & FHI/Impact, 2005 (98 p.)  
Pdf: [www.popcouncil.org/horizons/childrethics.html](http://www.popcouncil.org/horizons/childrethics.html)  
Hardcopy: [horizons@pcdc.org](mailto:horizons@pcdc.org)

This publication is designed for programme managers and researchers who work with children and adolescents, including those affected by HIV/AIDS. It identifies challenges and proposes practical approaches to dealing with children. It provides case studies that highlight the roles of research and programme staff in ensuring that child-related activities are conducted ethically.

## → Research reports & Reviews

**Young men and the construction of masculinity in sub-Saharan Africa: Implications for HIV/AIDS, conflict and violence.** G. Barker & C. Ricardo, Social Development Papers, World Bank/Conflict Prevention & Reconstruction, Paper No. 26, 2005 (96 p.)  
Pdf: [www.promundo.org.br/Pesquisa/Young Men SubSaharan\\_Web.pdf](http://www.promundo.org.br/Pesquisa/Young Men SubSaharan_Web.pdf)  
Hardcopy: Conflict Prevention & Reconstruction, Social Development Department, The World Bank; 1818 H Street, NW, Washington DC 20433, USA  
fax: +1-202-522-3247; [cpr@worldbank.org](mailto:cpr@worldbank.org)

The main objective of this research was to build a stronger understanding of the role of men and boys in the perpetuation of violence and the spread of HIV/AIDS

in sub-Saharan Africa and the kinds of programme interventions that can support alternative versions of manhood.

**MAP report 2005: male to male sex and hiv/aids in Asia.** Monitoring the AIDS Pandemic (MAP) Network, 2005 (24 p.). Pdf: [www.mapnetwork.org/reports.shtml](http://www.mapnetwork.org/reports.shtml)

This publication reviews the HIV/AIDS situation of men who have sex with men (MSM) in Asia. The report summarises the key epidemiological findings among Asian MSM and discusses the programmatic implications of these findings. MAP also published two other overview reports in 2005: Drug injection and HIV/AIDS in Asia, and Sex work and HIV/AIDS in Asia.

## Exchange

on HIV/AIDS, sexuality and gender

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**Line-editing:** Tendayi Kureya, Zimbabwe

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## → Factsheets & Issues briefs

**Educate girls, fight AIDS.** Global Coalition on Women and AIDS, 2005 (4 p.)  
Pdf: [www.planetwire.org/files.fcgi/5455\\_FightAIDS.pdf](http://www.planetwire.org/files.fcgi/5455_FightAIDS.pdf)

Growing evidence shows that getting and keeping young people in school, particularly girls, dramatically lowers their vulnerability to HIV. This issues brief examines the evidence.

**HIV/AIDS in Asia: Human rights and the education sector.** J. Wijngaarden & S. Shaeffer, Discussion Paper No. II, UNESCO Bangkok, 2005 (4 p.)  
Pdf: [www2.unescobkk.org/elib/publications/HIV\\_AIDS\\_EDU2/index.htm](http://www2.unescobkk.org/elib/publications/HIV_AIDS_EDU2/index.htm)

This paper discusses how HIV/AIDS threatens human rights in the education sector, and how the sector can be mobilized to protect rights in the context of HIV/AIDS.

**Gender-based violence and HIV among women: assessing the evidence.** AMFAR/American Foundation for AIDS Research, 2005 (2 p.)  
Pdf: [www.amfar.org/binary-data/AMFAR\\_PUBLICATION/download\\_file/38.pdf](http://www.amfar.org/binary-data/AMFAR_PUBLICATION/download_file/38.pdf)

This issues brief reviews the evidence on the links between gender-based violence (GBV) and HIV among women, both as a cause of HIV infection as well as a consequence.

## → Books & Other resources

**Preventing HIV/AIDS in the Middle East and North Africa. A window of opportunity to act.** (2005). F. Ayodeji Akala & C. Jenkins, Orientations in Development Series. World Bank publication, ISBN: 082136264X (110 p.)  
Pdf: <http://siteresources.worldbank.org/INTHIVAIDS/Resources/375798-1127498796401/082136264XPreventingHIV.pdf>  
Hardcopy: <http://publications.worldbank.org> (\$10 + postage)

This World Bank book argues that greater investments to improve HIV/AIDS advocacy, developing an information base, and implementing prevention strategies among high-risk groups in the Middle East and North African

region are needed now, before prevalence levels reach epidemic proportions.

**Annotated bibliography – Gender, HIV/AIDS and development.** ICAD (Interagency Coalition on AIDS and Development, Canada), 2005 (8 p.). Pdf: [http://icad-cisd.com/content/pub\\_details.cfm?ID=156&CAT=9&lang=en](http://icad-cisd.com/content/pub_details.cfm?ID=156&CAT=9&lang=en)

This document compiles key online resources that describe the current understanding of, and responses to, the effects of gender on HIV/AIDS at the international level. A special focus on gender-based violence is included.

All resources are accessible through our website: [www.kit.nl/exchange](http://www.kit.nl/exchange)