



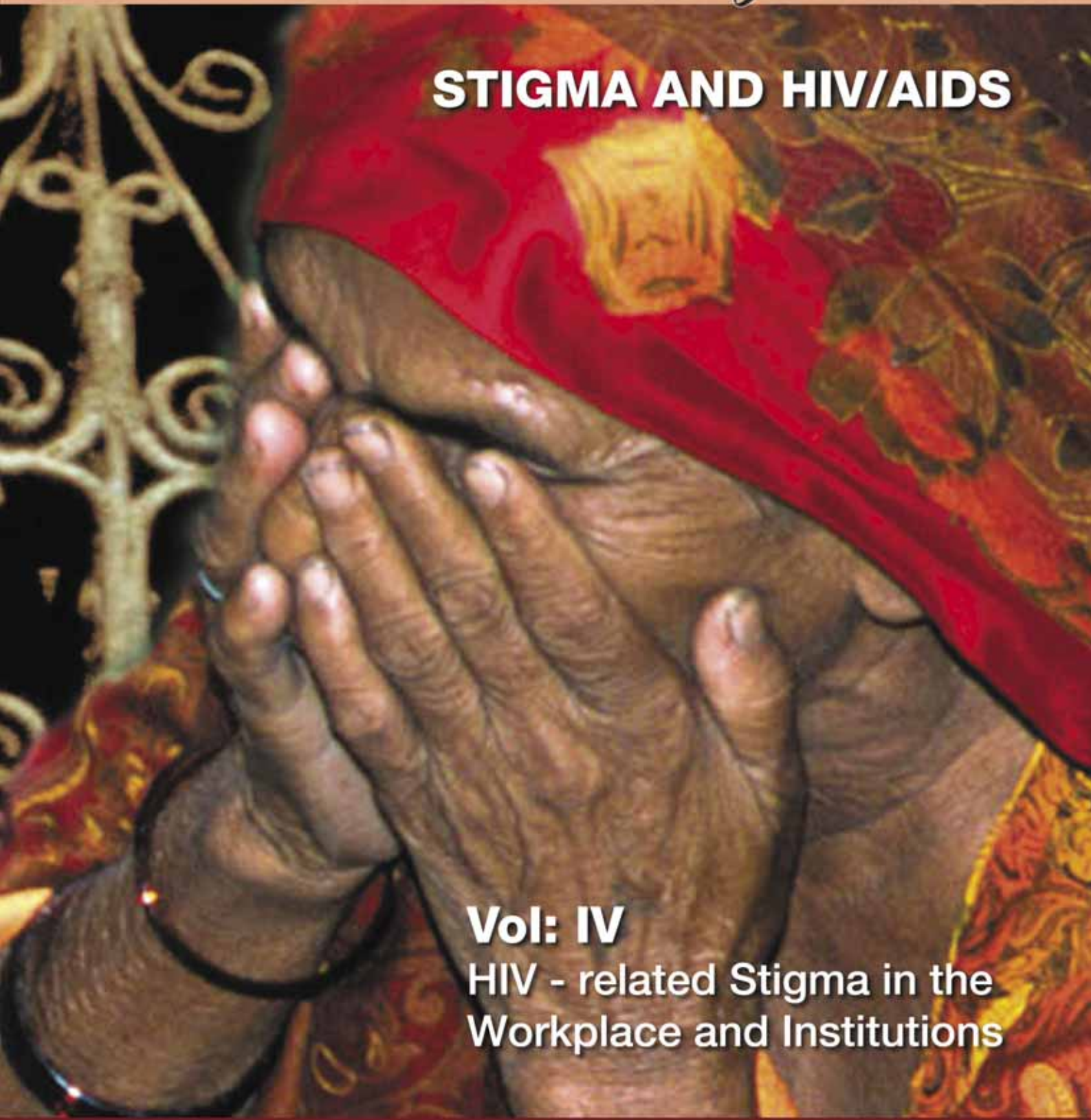
THE CORRESPONDENT

dialogues

Comment and analysis from the HDN KC Team

Issue No. 12 IV

STIGMA AND HIV/AIDS



Vol: IV

HIV - related Stigma in the
Workplace and Institutions

HIV-related stigma and discrimination in the workplace and institutions

Summary of Stigma-AIDS eForum discussion



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We welcome your comments and feedback

To read the Stigma-AIDS eForum archive please visit www.healthdev.org/eforums/stigma-aids

The views expressed in this paper do not necessarily reflect those of HDN or IFRC.



Introduction

Stigma-AIDS is a time-limited, global forum on HIV- and AIDS-related stigma and discrimination¹. The forum is managed by Health and Development Networks (HDN), working together with the International Federation of the Red Cross and Red Crescent Societies (IFRC), the Global Network of People Living with HIV/AIDS (GNP+) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) on the IFRC global campaign against HIV/AIDS-related stigma and discrimination: 'The Truth About AIDS. Pass it on...', launched in 2002.

The objective of the forum is to provide a place where knowledge, experience and practical solutions about stigma and HIV can be discussed and shared among people from all regions. Building on the informative structured discussion held on Stigma-AIDS in 2001, the 2003-2004 discussions focused on bringing local, national and regional experiences of HIV-related stigma to the forefront. It has fostered new partnerships between forum members and promoted discourse among people from different professions about both stigma and discrimination, by increasing the direct participation of a wide range of people, sectors and communities, predominantly from countries in the global South.

This initiative aims to increase the impact of the response to stigma and

discrimination by: facilitating and supporting information exchange, discussion and transparency among HIV and AIDS actors worldwide; documenting stigma issues at HIV and AIDS-related events; increasing coordinated participation of new and existing partners; facilitating long-distance learning; and encouraging exchange of ideas.

This document is one of four produced after each theme chosen for discussions during 2003-2004. These were selected following an extensive literature review and were:

- Stigma, HIV/AIDS and injecting drug use (2003)
- HIV and self-stigma (2003-2004)
- Stigma, HIV/AIDS and disclosure (2004)
- HIV-related stigma and discrimination in the workplace and institutions (2004)

Each discussion was moderated in a structured way, using the process of deliberative dialogue as the basis. A launch piece was sent out to members together with a set of moderator questions to guide the discussions. Key Resource People then contributed papers to focus and guide the discussions based on their recognised experience and expertise in the field.

This document provides a summary of the main points outlined in the contributions

received during the final discussion: HIV-related stigma and discrimination in the workplace and institutions. It reflects the major themes highlighted in the discussions and presents perspectives from countries in every continent. Discussions took place for 4 weeks in May and June 2004.

The full text of the discussions can be read at:
www.healthdev.org/eforums/Stigma-AIDS

'Living on the Outside' a primer presenting key findings and recommendations on how HIV stigma can be tackled, based on the eForum discussions is also available from Health and Developments Networks (HDN).

To request a copy of this or any other HDN publications please write to publications@hdnet.org

¹ Throughout this document, the term 'stigma' refers to the social and cultural construction of people living with HIV/AIDS (PWHA): associated with real or perceived beliefs and perceptions. The term 'discrimination' refers to the act of discriminating – rejection, denial, discrediting, disregarding, underrating and social distance – behaviour that is harmful, intolerant, discrediting, disregarding, underrating or prejudicial against people affected by HIV or AIDS.



Executive Summary and Recommendations

HIV-related stigma in the workplace exists across the globe and there were several accounts of serious workplace discrimination and violations of employees' rights. It is not possible to deal with HIV-related stigma until we understand it; education per se may not change attitudes. Because HIV-positive people often live on the margins of poverty, having a job is extremely important, allowing them to eat nutritiously, pay for health care and live longer. Living with HIV therefore means one is more susceptible to loss of livelihood.

Few HIV-positive people shared personal experiences of being made to feel welcome, comfortable or safe to declare their status within the workplace, and in many situations people face "murderous prejudice" in the workplace. Often it is up to the individual to break down attitudes of colleagues and employers. Themba Kubheka of South Africa was one of the few who wrote about her personal experiences within the workplace and her perspective of how to facilitate disclosure of HIV status.

Lack of information regarding HIV and AIDS is one contributory factor leading to HIV-stigma in the workplace, and interestingly workplace discrimination is not restricted to resource poor countries. In Greece,

for example, there is a dearth of AIDS awareness programmes in the education system, and there is little or no basic knowledge regarding HIV in the community or the employment sector. Again and again contributors to the discussion said that a lack of basic knowledge about HIV transmission is responsible for fuelling stigmatised attitudes in the workplace. This culminates in most people hiding their status, living with the burden of their secret, and often missing out on valuable support from friends as well as essential medical care.

Most people saw the solutions to AIDS-related stigma in the workplace to be a combination of developing sound policies and practices that ensure workers have information and access to care, promoting sound legislation that protects workers rights, and developing strong partnerships between private and public sectors that include HIV-positive people. Interventions to reduce stigma and discrimination include: legislation; development of workplace policies; and increasing commitment to greater involvement of people living with HIV/AIDS (GIPA). There is also evidence that the private sector can create appropriate working environments for people living with HIV/AIDS (PWHA). Some non-government organisations (NGOs) and international agencies, such

as the United Nations Children's Fund (UNICEF) have developed comprehensive HIV and AIDS programmes, though even here a lack of knowledge was discovered to be common.

From the points made at the close of each section of this document, there are a number of key recommendations that should be considered by all those involved in the HIV/AIDS response in order to help tackle stigma in the workplace and institutions:

1. The workplace exposes PWHA to distinct manifestations of stigma and discrimination – appropriate policies must be in place to protect the livelihood, security and support of affected people.
2. Models of good practice should be used to inform all initiatives, and in particular the provision of information, and involvement of affected people can have a significant impact in the workplace.
3. In line with broader initiatives, the need for a human-rights based approach is paramount, embedded in robust employment legislation.
4. Pressure must be brought on both the public and private sectors to set specific targets for developing appropriate policies.



Overview: Stigma and Discrimination in the Workplace and Institutions

By now many of us recognise that HIV and AIDS-related stigma continues to be a major barrier to a successful response to the HIV pandemic. Many institutions appreciate that increasing the meaningful involvement of HIV-positive people can help mitigate HIV and AIDS-related stigma and increase the acceptance of people living with HIV. It is widely acknowledged that such involvement must be across all sectors and at every level of our response to HIV. Involving HIV-positive people can have a positive effect on their own physical and psychological health as well as attitudes of the colleagues with whom they interact and the programmes into which they have active input.

HIV-positive people bring the unique perspective of their experience to institutions working in the field of HIV and AIDS, or any other, and have proved to be very effective educators, counsellors, support workers, and policy-makers. The Horizons Project (2002), which studied the involvement of HIV-positive people in community-based organisations in Africa, Central America and Asia, suggests the involvement of HIV-positive people is important in several ways, including:

- Increasing the sensitivity of HIV-negative [or untested] people to the realities of HIV and the needs of HIV-positive people;
- Improving the quality, appropriateness and effectiveness of services offered;
- Improving prevention efforts.

UNAIDS describes a pyramid of involvement of HIV-positive people from a base where their involvement is as targets or recipients of services and interventions, to an apex of involvement as decision-makers. Stigma is the greatest challenge to involvement of HIV-positive people at the apex of the pyramid.

There is a great deal of well-founded fear in opening up about one's HIV status in the workplace. The Asia Pacific Network of

Positive People [APN+] has documented HIV-related discrimination in Asia (APN+, 2003). Of the 753 respondents in the study, 10% faced discrimination by colleagues, 7% lost their jobs and 9% had their job description or duties changed because of their HIV status. Twenty percent of HIV-positive people experienced workplace discrimination after diagnosis in their workplace. HIV-related workplace discrimination is real.

According to a study in India by Bharat et al (2001), the majority of HIV-positive people keep their status secret in the workplace for fear of HIV-related discrimination and its negative impact on their livelihood. The workplace is among the least likely of settings where people disclose their HIV status. People, whose status is known, experience discrimination from both management and co-workers. The subsequent invisibility of HIV in the workplace leads management to deny the reality of the virus or to refuse to acknowledge it as a major health problem.

In most developed countries, these problems may be less acute because HIV-positive citizens often have legal protection via anti-discrimination legislation, and they are more likely to get access to antiretroviral drugs and thus stay healthy and not have to disclose their status in the workplace. Nevertheless, discrimination still occurs because of people's unfounded fears. There have been several high profile cases of HIV-related discrimination within the entertainment industry (Cirque du Soleil) and the sporting arena (Magic Johnson). Many cases of workplace HIV discrimination have also been reported within the hotel industry. Within the HIV and AIDS sector it may be easier for people to disclose and get support, but even here many HIV-positive people are reluctant to be open, as we heard from Robert Baldwin of the Australian Red Cross, in the previous discussion on disclosure.

The response towards HIV and AIDS issues in the workplace has been a fragmented

one. The Global Business Coalition on HIV/AIDS and the International Labour Organisation (ILO) are leading the way with some progressive thinking. The ILO, for example, recognises that the epidemic affects the workplace in several ways:

- Discrimination against HIV-positive people;
- Decrease in supply of labour;
- Loss of skills and experience;
- Decrease in productivity and rising costs of labour;
- Undermining of investment;
- Increased burden on women who have to earn a livelihood and provide care to family members.

The ILO has developed a Code of Practice on HIV/AIDS and an accompanying training manual for employers and supervisors (ILO, 2001).

Workplace policies on HIV/AIDS have now been developed in many institutions. They include supporting all HIV-positive people, whether they want to be open about their HIV status or not, and protecting those who are open so they do not face ostracism from co-workers or loss of services available to others. However, workplace policies vary in offering access to life-saving antiretroviral medicines, which is fundamental to sustaining meaningful involvement of HIV-positive people. This is a topic of increased debate as costs of antiretroviral therapy drop to accessible levels. Various trans-national corporations - such as some African mining companies and banks - have progressive policies and do provide antiretroviral drugs, however the rationale is perhaps based more on economic rationalism than a realisation of rights. On the whole, companies have not yet managed to create enabling environments that encourage significant numbers of employees to test. These same companies should now be encouraged to create an enabling environment for voluntary testing by employees.

Some United Nations, international and



national institutions, and NGOs working on HIV and AIDS, have moved beyond denial to embrace the employment of openly HIV-positive people – UNAIDS is a case in point. Many such employees have been pivotal in shaping new policies and programmes and increasing understanding of HIV within the sectors in which they work, including the private sector. According to UN Volunteer (UNV) GIPA pilot projects in Africa:

The ultimate success of these projects has been extraordinary. The Projects have demonstrated that PWHAs and their involvement engender a dialogue within communities about how they can live with the epidemic and that PWHAs are part of the solution rather than the cause of the problem.
(Nairobi Consultation, February 2000)

The Nairobi consultation discussed the need to identify institutional indicators for stigma and stigma reduction and to generate professional codes of conduct. At the institutional level pre-conditions include laws to protect those who become involved. At the organisational level they include:

- Sensitivity training for colleagues;
- Information about opportunities for GIPA;
- Optimal use of existing skills.

A current campaign striving to eradicate HIV-stigma – in the workplace and other contexts – is ‘The truth about AIDS. Pass it on...’, a ten-year initiative of the International Federation of the Red Cross and Red Crescent Societies (IFRC) launched in 2002. The campaign aims to ensure that those people who are already HIV-positive are able to receive the appropriate care, have access to affordable drugs and live full and useful lives within their communities. It also aims to prevent further spread of the infection and increase individuals’ willingness to be tested. As part of the campaign, an internal eForum is open to all IFRC staff and volunteers.

Topics discussed have many parallels with those appearing on Stigma-AIDS, and taken together these eForums provide a powerful resource for the co-ordination of anti HIV-stigma activities.

The IFRC, in association with a number of other organisations, has recently distributed what could prove to be a significant document: an NGO Code of Practice on HIV/AIDS. This is targeted towards NGOs working with other HIV/AIDS NGOs and is particularly useful for institutions with little previous experience working in the field of HIV and AIDS. This Code of Practice aims to help organisations work together more effectively and includes guidelines on how to work with HIV-positive people.

Within some faith-based organisations, a major problem has been the range of responses towards HIV. Some African religious leaders are paving the way with the development of the African Network of Religious Leaders living with HIV/AIDS (ANERELA+), which was launched at the eleventh GNP+ Conference in Kampala, Uganda in 2003. Already, many religious leaders throughout Africa have come out openly and declared their HIV status. This will no doubt have a strong impact on their religious followers.

Politicians have also made bold statements by publicly presenting themselves for testing. Members of the Zimbabwean ruling party (Zanu-PF), and the opposition party (MDC), offered to be tested for HIV in order to ‘break the stigma associated with HIV’ (reported in Independent Online, 4th May 2004, and postings on the AF-AIDS eForum, archived here: <http://eforums.healthdev.org/read/messages?id=780>).

Some critics argue that the GIPA principles have rarely been grasped by key people with the responsibility to implement policies. HIV-positive people are invariably perceived as patients in need of care, or members of vulnerable groups - objects

of discrimination. There is a lack of understanding of how their knowledge and expertise can be harnessed most effectively and integrated to influence policies and programmes, and wider health agendas – a valuable opportunity is being lost. The challenge for employers is to differentiate between the role of HIV-positive people as service recipients and as policy and project designers.

Some HIV-positive people have been employed without terms of reference or guidance as to what their role is. Many have felt exploited rather than inspired by the positions into which they were thrust. HIV-positive people might require capacity-building in certain areas in order to fulfil their responsibilities as effectively as possible.

Another serious challenge in the workplace is the provision of relevant training opportunities to HIV-positive people working in HIV and AIDS organisations. Government bodies in particular rarely provide such opportunities. The majority of HIV-positive employees learn ‘on the job’ without previous experience or training in public health, organisational management, proposal writing, public speaking, counselling, and advocacy. Yet they need these resources to make an effective contribution

HIV-positive people may be used as tokens rather than involved as equal partners. Some organisations have been accused of employing HIV-positive people without genuine commitment to involving them at a policy-making level in order to indicate compliance with donor expectations and enhance funding possibilities. Institutions seem to rarely create support strategies such as training opportunities, or have the capacity to match HIV-positive people’s skills to service delivery needs. The Horizons study (2002) mentioned above confirms a lack of appreciation of the untapped potential of HIV-positive people.

Moderator Questions:

The eForum discussion began with questions from the moderator:

1. What, if any, stigmatising attitudes and/or policies have you faced in your workplace?
2. How much is stigma sustained by the organisation, and how much by individuals?
3. What, if anything, has facilitated people’s comfort in disclosing their HIV status to co-workers?
4. Does the organisation have adequate workplace policies around HIV to create a safe and supportive environment for HIV-positive people?
5. What examples of best practice have you seen in which people affected by HIV are able to disclose safely in their workplace without fear of prejudice?



1 Stigmatising Attitudes in the Workplace

HIV-related stigma exists in workplaces across the globe and there were several accounts of serious workplace discrimination and violations of employees' rights.

1.1 Personal stories

HIV-related stigma exists in workplaces across the globe and there were several accounts of serious workplace discrimination and violations of employees' rights. Most people are worried about disclosing their HIV-positive status to their employer or co-workers for fear of facing stigma and discrimination. An extreme result of workplace discrimination was reported in India, where a 34-year-old HIV-positive woman committed suicide after being taunted by her co-workers about her HIV status. A police official said, "She was pushed into despair because her colleagues teased her about her illness" (news report, April 26th 2004).

Key Correspondent Elena Obieta wrote about the testing of workers for HIV without their consent in Argentina, and the subsequent dismissal of one of her colleagues:

Fear of the unknown perpetuates self-stigma. That is what a middle-aged executive in a multinational company thought: Let's go from silence to visibility. So, as soon as he knew his serological status he decided to speak. This was also a defensive move. In case he was fired, everybody would know this had been because he was 'openly' HIV-positive. In other words, he decided to talk because, if his serological status came to light for the company owners by 'other means' (meaning through a violation of confidentiality) he could have been fired for no other reason, and very few legal arguments would help the employers in court.

Within months of telling everyone in his work place that he was HIV positive he was fired. A legal battle started and the discrimination trial was finally won by my patient, and the multinational corporation lost. At this point I am reminded of a message during the self-stigma and HIV/AIDS e-Forum discussion written by Charlene Smith, a South African journalist: It is more difficult not to disclose. It's more difficult to live a life that is a lie.

Elena Obieta (Argentina)

One anonymous contributor articulated the fear of being untested and being surrounded by people who

are immuno-suppressed, particularly people who have infections such as TB.

My fear comes from the fact that I do not know my status. If therefore I get infected from tuberculosis (TB) for example, by way of being near a patient with TB, then it will trigger the HIV I may have and at the end of the day, I may get to the AIDS status.
(Anonymous)

Qualitative research among miners in Papua New Guinea (PNG) indicated that people are extremely reluctant to disclose their status within the workplace. Most people believe that if they found out they were infected with HIV, they would not tell anyone until they got very sick and it became obvious, at which point many would resign themselves to early death, as well as to people talking about them and shunning them. Key Correspondent Jimmy Peter described education programmes organised in the mines by PNG Red Cross. He said that an extremely effective way to overcome discriminatory attitudes among colleagues has been to meet people who are living with HIV.

The thought of disclosing one's status to employers, employees, workmates and family members was so unthinkable and frightening because of the stigma and shame that they would bring upon themselves and their families. Barthly Sioni, an occupational health and safety officer with a drilling contractor, said, "I will not tell anyone until I am dying, but if I do tell people I am HIV-positive they will call me a 'payarais' [prostitute or promiscuous person] and I will be ashamed and neglected. Someone will tell my wife and I just don't even want to think what will happen to me. It is so frightening that I won't tell anyone about it. I will work until I can't work anymore, but I will never tell anyone."

One woman interviewed said that if she were HIV-positive, the consequence of disclosing her status, would be a terrible death for her and a terrible life for her family. "That is the way I see it, but maybe if we can really push this anti-stigma messages home, then it may not be so bad," she said.



But for 38 year-old Augustine Zykios, who runs a small environmental monitoring business, honesty is the best way to approach the issue. "If I were to be HIV-positive I would tell my boss and ask him to keep me at work until I was too sick to work. I would do the same for any of my employees who tell me they have the virus, and I would keep them until they were too sick to work."

When asked how Augustine arrived at this way of thinking, he said it was through the awareness carried out by the Red Cross in the 'Wet Canteens' where mine workers gathered to quench their thirst after a hard day or night of work.

In an attempt to address HIV stigma in the workplace, the Papua New Guinea Red Cross has organised an educational campaign in the Lihir gold mine, a major industry in PNG. This campaign features presentations to workers by Max and Maura, a couple living with HIV in the nation's capital Port Moresby. They undertake HIV awareness and advocacy work with the support of the National AIDS Council. The Lihir gold mine has a fly-in-fly-out workforce, so the message is carried to more people by the mine workers when they return to their homes

"I thought otherwise before, but when Max and Maura came to give their talk, I realised that there are so many years left in our lives after the initial infection and that people must work to be able to make money to make their lives more comfortable. We are all eventually going to die, so if I have to die of AIDS, I will die of AIDS and I will die with peace, and if others want to make it a problem, let them die with problems. I know I am one of the few people who think like this, but I aim to get more people on my side," he said.

Jimmy Peter (PNG)

1.2 The United Nations (UN) experience

Few HIV-positive people shared their personal experiences of being made to feel welcome, comfortable or safe to declare their status within the workplace. Within the United Nations (UN) system, some HIV-positive staff recounted good experiences, such as not having to hide their status and having subsidised triple drug therapy. Nevertheless, one HIV-positive UN employee said that whilst he found his work tremendously rewarding he found it hard to believe that so few UN staff are open about their HIV status. He feels that individual UN staff should each think about whether they can contribute to a more supportive environment. At the UN Games in May 2004, Kate Thomson from the International Community of Women living with HIV (at that time working for the Global Fund, whose staff members have WHO contracts), articulated some of the negative attitudes of UN staff towards people with HIV.

UN Secretary General Kofi Annan has been an outspoken

advocate in the battle against HIV and has on many occasions stressed the urgent need to take exceptional measures to halt the pandemic that rages across sub-Saharan Africa and other parts of the world. Nonetheless, in spite of efforts so far, the UN system is experiencing its own silent, internal epidemic. It is estimated that global prevalence within the UN system is at around 5% - obviously with some regions affected more than others. If the UN were a country it would be among the top 30 countries affected by HIV/AIDS. In Zambia a recent survey of staff working in one UN agency revealed that out of 44 respondents, over half are caring for people in their own homes - primarily orphans and the sick widows of their lost siblings - and many have up to 14 additional people in their own homes who they are supporting. The devastating effects of the pandemic are without doubt manifesting themselves in the lives of many UN staff. I'd like to share with you some disturbing quotes detailing recent examples of AIDS-related discrimination encountered by various people living with HIV in the UN:

- * My colleague told me he hated HIV, and people with HIV because when they came to his desk he had to disinfect everything;*
- * Someone suggested we should not recruit new staff from Africa because they'd all have HIV and die;*
- * A staff member asked why someone was having their contract renewed since he was dying (in fact although this person had HIV he was extremely healthy);*
- * Staff in our office do not want to eat food prepared by people living with HIV;*
- * People in my team make jokes about AIDS assuming that nobody has HIV in the room;*
- * Team members suggest that people who are living with HIV are only hired because we feel sorry for them - implying we are not competent;*
- * Some say that staff with HIV should be fired and sent back to their countries;*
- * People have been asking how we dare to make exceptions for HIV - why help bad people when they deserve it;*
- * It was suggested in our office that the UN should create a media campaign saying that HIV+ women should not be allowed to have babies;*
- * Some people have suggested we test everyone and put them into separate vehicles when we travel so that if there is an accident the 'innocent negative' staff won't be put at risk...*

These voices of people living with HIV from the UN system give us some indication of how far we still have to go to get our own house in order. Stigma and discrimination must be confronted at all levels and all staff must be sensitised and educated on HIV/AIDS. The GIPA principles must be truly valued and implemented throughout the UN system and not just be paid lip-service, which is all too often the case.

Kate Thomson (UK)

Within the United Nations (UN) system, some HIV-positive staff recounted good experiences, such as not having to hide their status and having subsidised triple drug therapy.



HIV and AIDS-related stigma stems from a lack of awareness about the disease and from the various myths and misconceptions regarding its routes of transmission.

1.3 Fundamental problem – a lack of information

Rumeli Das, a Key Correspondent from India, said HIV and AIDS-related stigma stems from a lack of awareness about the disease and from the various myths and misconceptions regarding its routes of transmission. A moving case study described by Dr Das spoke of the immense difficulties faced after an HIV diagnosis: Striving to control depressions, the fear of losing a job if the status becomes widely known, and the solace found in meeting other people living with HIV:

Though HIV is not transmitted in the majority of workplace settings, the supposed risk of transmission has been used by numerous employers to terminate or refuse to employ PWHAs... HIV-related stigma and discrimination remains an immense barrier to effectively fight the most devastating epidemic humanity has ever known. People with, or suspected of having, HIV are often turned away from health care services, denied housing and employment, shunned by their friends and colleagues, turned down for insurance coverage or refused entry into foreign countries. Fear of discrimination prevents them from seeking treatment for AIDS or acknowledging their HIV status publicly. People living with HIV/AIDS who earn their livelihood through service face similar discrimination from their workplaces... The widespread belief that HIV/AIDS is shameful, along with the customs and norms of a society can increase the stigmatisation of people with HIV/AIDS in the workplace. This prevents people from reaching out a compassionate hand to their HIV positive colleagues...

I am a working woman in my forties infected with HIV. I thought I could cope with the situation if I could divert my mind with work. I tried to continue my usual routine of going to the office everyday. But as my health was not good I couldn't make it everyday. Still, I wanted to continue my job as it would help me to forget about the disease for sometime. My friends and colleagues were also very worried. They often asked me about my health and wanted to know what the problem was. But initially I was afraid to reveal my HIV status to them. Owing to my illness I had to remain absent from work for many days. In order to get the permission for my leave I had to tell my supervisors about my HIV-positive status so that they could arrange for sick leave. It was then that some of my colleagues came to know about my HIV status. When they first heard about it they were shocked. They could not believe that this could happen to me, as they know me well.

In spite of this I am not in a position to disclose my HIV status to other colleagues because I fear that they will not

accept the fact and may stigmatize me or discriminate against me. Our society has not yet become so liberal that they can all accept an HIV-positive person wholeheartedly. I also fear that I may lose my job if my HIV status is disclosed to all my colleagues, which I do not want. This job has helped me to overcome my problems to a great extent. I can continue my treatment, which is quite expensive. This would otherwise be difficult for me if I lost my job.

Rumeli Das (India)

HIV-related workplace discrimination is not restricted to resource poor countries. In Greece, for example, Calliope Tavoulari said there is a dearth of HIV and AIDS awareness programs in the education system, and there is little or no basic knowledge regarding HIV in the community or in the employment sector:

To my personal knowledge there are hardly any HIV-positive individuals that are working in any section of the employment field in Greece. The few exceptions that exist are employed primarily within AIDS institutions and crisis centres.

Greeks still exist in a tight knit community where everybody knows everyone else. Families are the major unit of society and therefore it is practically impossible to be discreet about your status. Still, there are laws that protect privacy and therefore it is not legal to subject people to obligatory examinations or learn about somebody's status unless they disclose it to you themselves.

Being a close community has its advantages and disadvantages. Families take care of their own people to make up for the social welfare gap but it also leaves little personal privacy. It is certain that there are laws that protect people against blatant discrimination, but what about psychological discrimination and stigmatisation? It's easy to say that the law protects your right for employment, whatever your status, but what exactly protects you from other people's ignorance and indifference? This is the primary issue with HIV-positive individuals here in Greece and this is what has cut them off from living a normal active and productive life...

Currently there are no governmental programmes that integrate PWHAs within the employment field, although I was informed that steps have been taken by the Athenian AIDS Crisis Centre that they are planning to submit a proposal for such programmes that will be funded by the European Union. I am also aware that the Hellenic Red Cross Society signed a pledge to combat stigmatisation and discrimination in the 28th National Conference of the Red Cross and Red Crescent Societies, that was held in Geneva during December, and this could only mean that we will

To my personal knowledge there are hardly any HIV-positive individuals that are working in any section of the employment field in Greece.



be making small but certain steps towards correcting this stagnant situation that exists within our community.
Calliope Tavoulari (Greece)

Again and again contributors to the discussion said that a lack of basic knowledge about HIV and its transmission is responsible for fuelling stigmatising attitudes in the workplace. This culminates in most people hiding their status, living with the burden of their secret, and often missing out on valuable support from friends and essential medical care to keep them healthy.

1.4 Caught in a dilemma – the need for employment

Like anyone living on the margins of poverty, having a job is very important to most people living with HIV. It allows them to eat nutritiously, pay for any necessary health care, stay healthy, and live longer. Maintaining rewarding employment is crucial but paradoxically having HIV means one is more susceptible to loss of livelihood. A survey conducted by the Thai Business Coalition on AIDS found that 45% of surveyed PWHA are either unemployed or without a regular source of income; 95% of those reported an income loss due to HIV.

According to Amrik Kapoor of India, a study conducted by the International Labour Organisation (ILO) in Delhi, Maharashtra, Manipur and Tamil Nadu examined stigma and its impact on employment status, family income, expenditure and availability of care and support, for 292 HIV-positive respondents and their families. HIV-related stigma had an impact on hiring, firing and promotion policies, work allocation, pay and benefits, attitudes of employers and other employees, and employment security. The study found that HIV/AIDS NGOs and networks were most sensitive to and supportive of HIV-positive employees needs. Amrik described a range of workplace violations at local Indian hospitals, among hotel employees and in the public sector. Often people who were well-liked prior to their HIV-positive status becoming public became sudden outcasts from their co-workers. Overcoming such discriminatory attitudes requires many hours of education within the workplace. Some cases of HIV-related workplace discrimination have been successfully fought within the Indian judicial system

Despite years of educational work by the government,

Overcoming such discriminatory attitudes requires many hours of education within the workplace.

non-governmental organisations (NGOs), networks of people living with AIDS (PWHA) or pious declarations by political bigwigs, stigma and discrimination due to HIV persist. The workplace, like one's family and society anywhere, is no exception in India.

The President of the Network of Maharashtra People Living with HIV/AIDS feels that, 'It is not the disease which is wiping out people but the discrimination.' Sharing his views with the Times News Network (TNN), he asks, 'If you do not get a job, how will you survive?' Cases of stigma and discrimination in the workplace are increasingly common. Recently the Bombay High Court directed the New India Assurance Company, to give permanent employment to an HIV positive woman. The court ruled that denying people jobs on the grounds of HIV status, was discriminatory and a violation of their fundamental rights...

Instances of blackmailing by employers and threats to disclose HIV status were cited by respondents in the [ILO] study. The behaviour of co-workers is also an important issue. Sadly, there were many instances of respondents feeling neglected or isolated by their co-workers. Indifferent behaviour forced respondents to change their jobs frequently. Some were also asked to quit their jobs. Respondents also faced verbal abuse, lack of cooperation from colleagues and breaches of confidentiality regarding their HIV status. One respondent was fired.

In cases where the employers were not supportive, the respondents had to face demotion or find a new job where no one knew they were HIV positive. Many had to use up their savings, sell or mortgage assets, borrow from others or stop taking medicine.
Amrik Kapoor (India)

Acknowledging that ignorance about many aspects of HIV is causing many Africans to lose their livelihoods, a BBC news report quoted South Africa's High Court judge, Justice Edwin Cameron, when he called for Africans to approach HIV/AIDS with reason and fairness and for a continent-wide effort to battle HIV discrimination in the workplace.

Stigmatising attitudes in the workplace: specific points of concern

As can be seen from these contributions, HIV-related stigma and discrimination in the workplace can add extra layers of distress and tension for the PWHA. Issues of confidentiality and loss of employment are real. Are employers naturally discriminatory towards PWHA, placing profit above social support?

Evidence of good practice can be found in the UN: though even here there is evidence of negative attitudes and behaviour. It is not surprising that people choose to withhold information about their HIV status from co-workers. However, issues around disclosure in this context are complex, and this is discussed in section 2 (below).



2 Disclosure in the Workplace

My boss was genuinely concerned for my health and well-being, and so were my colleagues. Over time, we discussed HIV and issues around it, and we all came to a greater understanding of the illness itself and of attitudes around it.

2.1 Coming out

Paul Clift, a contributor from the United Kingdom acknowledged the ‘murderous prejudice’ that people face because of attitudes to HIV; at the same time he addressed the need for more HIV-positive people to come out in the workplace, providing they have a safe environment. Paul came out in his workplace in the UK before the advent of triple combination therapy and found a very supportive atmosphere and one in which he and his colleagues gained a greater understanding of HIV-related issues. He suggested that HIV-positive people can challenge stigma and discrimination by the way they present themselves – either as people with an infection who have equal rights, or as victims.

In my very personal opinion, those of us who can be open about our status should be open about it, so that we can gradually sensitise the wider populace to the fact that people with HIV are people.

I was diagnosed in 1988 in England, before combination therapy and at a time when anti-HIV prejudice was rife. At the time I was working in a major institution in central London. I decided to take the plunge and inform my work colleagues. This was a gamble, but some careful thought beforehand led me to believe that it was a gamble worth taking and thankfully it paid off. My boss was genuinely concerned for my health and well-being, and so were my colleagues. Over time, we discussed HIV and issues around it, and we all came to a greater understanding of the illness itself and of attitudes around it. All of us gradually came to view it as a health issue, a social issue and a political issue, but never was it an issue of stigma and never was I subjected to prejudice because of it.

I realise that this incredibly helpful and supportive reaction is not the standard that all PWHAs can currently

expect, and that I was working in an environment of broadly liberal attitudes. However, a similar experience developed in my next job, working in a university library in a town on the southern English coast. Although I made no mention of my positive status in the job application process, I let it become known after a few months in the post. Again, my work colleagues’ responses were broadly supportive; there was some concern about my health (this was still pre-HAART) and general well-being, but nothing negative or discriminatory.

While harsh attitudes and practices do exist, I feel that as people with HIV/AIDS we have to be careful about how we present ourselves to others and to ourselves: are we simply people with an infection (and therefore every right to an equal place in society) or are we victims - in other words, do we agree to be stigmatised or do we challenge it? How do we challenge it? If we are not strong enough to challenge it (and there is no shame in that) how do we show support for those who do stand up in the face of it?

As ever, the more people disclose their status, the more familiar the wider population becomes. This is particularly the case if people in influential positions ‘go public’ about having HIV, for example faith leaders. With this, and with - hopefully - wider access to ARVs (which is another argument entirely!) I firmly believe that HIV-stigma will gradually diminish.

Paul Clift (UK)

Another contributor, Richard Yell suggests that it is not possible to deal with HIV-related stigma until we understand it – education per se may not change attitudes. He outlined five major components of stigma: denial, ignorance, fear, contempt and guilt. He also said that it is imperative to involve positive people in all HIV/AIDS interventions if the interventions are to be successful:



I think that before we look at what organisations should or should not be doing, let's first try to understand STIGMA a little better... Alcoholism has shown me that education alone, even if delivered by 'absolute experts' is not what changes attitude and behaviour in our society, particularly where corporate interventions are concerned.

I believe it imperative to involve HIV-positive people in any intervention that an organisation may wish to implement, just as it is essential to involve alcoholics and addicts in any chemical dependency interventions. As an expert on dealing with stigma and prejudice based on my own life experience, I have discovered that stigma is primarily made up of 5 major components in the context of HIV/AIDS and alcoholism:

- DENIAL – The age-old 'it will never happen to me' syndrome – the problem thus lies with others;*
- IGNORANCE – It is easier to sweep issues under the carpet that we do not wish to face;*
- FEAR – A deep fear that we may discover a truth about ourselves that we will not like/manage;*
- CONTEMPT – A fire so often fuelled by activists and campaigners who continually fight reality;*
- GUILT – A by-product of dilemmas we discover that apply to ourselves, often based on SHAME.*

Many... organisations think if they wear a ribbon and knock up a condom machine in their staff toilets, they have done their bit. Wearing a ribbon is thus often a token, and tokenism is the flipside of the prejudice coin. So, love us or hate us, people need us in the process of stigma-busting at all levels, as well as to influence hearts and minds out there in order to shift attitudes and behaviours.

Richard Yell (South Africa)

2.2 Benefits of coming out in the workplace

Often it is up to the individual to break down attitudes of colleagues and employers. Themba Kubheka of South Africa was one of the few HIV-positive people who wrote about her personal experiences within the workplace and her perspective of how to facilitate disclosure of HIV status. She

Often it is up to the individual to break down attitudes of colleagues and employers.

also described the negative impact of her HIV diagnosis. At the time, she was working for the South African National Defence Force and when she received her test results she received no counselling – the doctor simply told her that 'now you are going to die'. Themba became very depressed and felt she would never be employable again. She believed she would die soon and was unaware of any army policy for soldiers found to be HIV-positive. Themba has since found satisfying work where she is open about her status and she described the strategies she uses as an employee living with HIV.

I enjoy working especially with the kind of colleagues I am working with at present. They all know that I am HIV-positive, but they sometimes forget - as there is more to life at work than HIV, and as they are also getting sick sometimes. They also forget not only because HIV is not written on my forehead, but they have learnt to live positively with my HIV i.e. I cannot infect them by talking, touching, hugging or eating together. The fact is I am alive and subject to all forms of different and individual human behaviours. We work as a team, we assist each other whenever needs be, so I am not a burden.

This is what I believe helps me survive at work as an employee living with HIV:

- *A realistically positive attitude towards my customers, work and colleagues.*
- *Creating and living in a happy working environment heals, instead of resigning.*
- *Consult and gather as much information and resources as possible, on living with HIV and share them with colleagues.*
- *Vigilance against any emotional and opportunistic illness challenges.*
- *Knowing, understanding, and protecting my rights.*
- *Put forward proposals and suggestions on the HIV and AIDS workplace programme.*

Themba Kubheka (South Africa)

Disclosure in the workplace: specific points of concern

Coming out about one's HIV status in the workplace can have potentially both positive and negative results. Some of the points raised in this section integrate with the previous stigma-AIDS eForum discussion on disclosure, but as can be seen here, the issues are in many ways magnified and more focused, the workplace being a relatively closed environment. Clearly, interventions by the employer can provide a forum for support and empowerment, but why do employers not do more? And how can PWHA be assisted in dealing with stigma and discrimination in the workplace?

Suggestions for interventions are discussed in the next section.



3 Interventions

Where workers are covered by anti-discrimination legislation, it may still not protect them, and discrimination may still occur.

3.1 Legislation

The Indonesian Minister of Manpower and Transmigration, Jacob Nuwa Wea, recently issued a decree on HIV/AIDS prevention and control in the workplace, which bans employers from discriminating against workers with the virus. The decree requires employers and labour unions to protect workers from discriminatory treatment and to disseminate information and organise education and training on HIV/AIDS. It also prohibits employers from performing HIV tests as part of their recruitment programmes or regular medical check-ups. However, the Indonesian Employers Association urged the government to exempt labour exporting companies from abiding by the decree because receiving countries require blood tests on migrant workers. Nuwa Wea said that with the issuance of the decree, he hoped HIV/AIDS prevention in the workplace will be more effective and he called on employers and trade unions to support the campaign for the prevention and control of HIV. In one respect, however, the decree's effectiveness is questionable because it fails to spell out the penalty for those who ignore the regulation.

In many countries there are legal frameworks to fight workplace discrimination. In the United States the Disabilities Act prevents discrimination based on HIV status if the person poses no real risk to themselves or others. A US news report posted on the forum, from gaywired.com in May 2004, described a lawsuit filed under the act by a man pursuing unfair dismissal. This is a rare example of anti-discrimination legislation being used to protect the rights of HIV-positive employees:

Joey Saavedra, a skilled auto glass installer who has worked in the industry for nearly 27 years disclosed his HIV status during an interview for a job with Nodak Enterprises. He was hired, but when he mentioned that he is HIV-positive to the company's district manager, Saavedra was fired three months later.

His dismissal had nothing to do with job performance, and his immediate supervisor wanted to keep him on the job said Lambda Legal, which is representing Saavedra.

Nodak Enterprises' termination notice said, 'HIV status is a direct threat to the safety of others... it is in the best interest of this Company to terminate the employee at this time.'

'Joey Saavedra was fired out of fear and bigotry - not sound science - and that is against the law' said Greg Nevins, Senior Attorney in Lambda Legal's Southern Regional Office in Atlanta.

Lambda Legal recently won the largest settlement of its kind against Cirque du Soleil when the company agreed to pay \$600,000 to gymnast Matthew Cusick after they unlawfully fired him because he has HIV.
US news report, May 2004

Where workers are covered by anti-discrimination legislation, it may still not protect them, and discrimination may still occur. In South Africa, despite legislation that protects the rights of employees living with HIV/AIDS, discrimination prevails, particularly against domestic workers. Good legal frameworks do not necessarily change mindsets. There is a continuing lack of basic information about HIV transmission and a lack of any real dialogue within most communities and workplaces about behaviour that facilitates HIV transmission, even though South Africa is one of the countries most heavily affected by HIV/AIDS. Some companies provide education only for perceived 'high-risk' employees - low or semi-skilled workers; they fail to realise that everybody, including the educated, is at risk.

South Africa has implemented a UN GIPA programme to give a 'face' to HIV. The project employs openly HIV-positive people and places them in private companies and government departments to 'to enrich workplace HIV/AIDS policies'.



Under [South Africa's] Employment Equity Act of 1998, 'no person may unfairly discriminate, directly or indirectly, against an employee, in any employment policy or practice, on one or more grounds, including ... HIV status'. The act also prohibits testing of an employee to determine their HIV status unless the Labour Court justifies such testing. But three years after the law was passed, not much had changed, Joni said [Jennifer Joni, an attorney for the AIDS Law Project]. The AIDS Law Project has noted a disturbing rise in the unfair dismissal of HIV-positive domestic workers. Domestic workers are particularly vulnerable, as they sometimes cannot claim the full benefits of the labour and employment laws.

"These workers have no bargaining power whatsoever", Joni noted. "Once they discover their employees are pregnant, an increasing number of employers are sending them for an HIV test, and if they are positive they are dismissed." Joni blamed this on ignorance. Employers don't know enough about HIV transmission and assume the worst.

Brett Anderson-Terry, a consultant providing HIV/AIDS management and awareness training to corporations, agrees. "The key thing is a lack of knowledge... I am still getting people asking me about mosquitoes [as a method of HIV/AIDS transmission] and this is from all kinds of South Africans - white, black, educated people. People still think this is something you get when you have been promiscuous", Anderson-Terry explained. "Just recently, some staff members in one of the companies I work with refused to eat in the canteen because they discovered that one of the kitchen staff was HIV-positive", he added.

Misconceptions about the disease and a sense of complacency among management are additional problems Anderson-Terry has had to contend with. "Some clients and staff members have told me I deserve to die and it is people like me that are causing the disease", he said...

Keith Markland, an HIV/AIDS coordinator for mining company De Beers, admits that workplace policies cannot effectively address stigma "because it can be very subtle". Beneath the hype surrounding recent announcements by some major companies in South Africa of their plans to provide HIV-positive workers with AIDS drugs has come a growing realisation that stigma might prevent many of their employees from taking advantage of the opportunity. "We are now rolling out our antiretroviral therapy programme but there is still a sense of mistrust about AIDS. These programmes are not going to work unless we get rid of all these attitudes," Markland said.

Stigma and discrimination remain the biggest hurdles, despite well-intentioned policies and drug programmes. Most HIV-positive staff members are afraid to disclose their status "because they don't know what's going to happen to them" Joni said. "You need somebody living with the disease to make it real. At the end of the day, CEOs have a job to do - they are there to make businesses

profitable so AIDS becomes secondary," Anderson-Terry noted.

IRIN News

3.2 The need for a workplace programme

Martina Clarke and Paul Sundry from UNICEF talked of the essential need for any workplace environment, particularly one operating in scores of countries and employing thousands of people such as the UN agency in which they work, to have a comprehensive HIV/AIDS programme for staff. They described the response of colleagues to meeting people with HIV as 'overwhelmingly favourable'. They also provided results of an unofficial pilot survey of a small sample of UNICEF staff, which revealed a considerable lack of knowledge about HIV. Half their sample believed HIV to be a contagious, fatal disease, and half of the respondents said they would be afraid to give a colleague with HIV mouth-to-mouth resuscitation in a life-threatening situation. Over 10% felt uncomfortable sharing an office with an HIV-positive co-worker. A majority of respondents also felt that UN positions are too dangerous for HIV-positive people because of the frequent travel and high stress requirements demanded by the jobs. The UN anti-discrimination policies prohibit pre-employment HIV screening, but only half of respondents felt this to be good. The UNICEF workplace policy that has been developed is partly modelled on the policies of the International Federation of the Red Cross and Red Crescent Societies (IFRC). However, comprehensive programmes are no guarantee of a workplace free of stigma and discrimination.

Our staff well-being programme called 'Caring for Us' provides all managers and staff with comprehensive guidelines for the communication of policies, prevention and transmission education for staff and their families, provision of free condoms, counselling and support, as well as access to antiretroviral therapy - if indicated, voluntary confidential counselling and testing and post exposure prophylaxis (PEP) treatment kits.

One of our most recent achievements to combat stigma and discrimination in the workplace was the creation of a video which shows staff members from around the world living with or affected by HIV/AIDS discussing the impact of living and working in a world with HIV/AIDS and how it has affected their lives. Modelled after an excellent video produced by the IFRC 'Living With...', our UNICEF video is the first of its kind in the UN System. This takes HIV/AIDS in the workplace from a 'politically correct' and mechanical set of policies and procedures to a highly personal experience. For many, the viewing of the video

The UN anti-discrimination policies prohibit pre-employment HIV screening, but only half of respondents felt this to be good.



was the first time the human face of a colleague touched by HIV/AIDS has been put on the pandemic in the workplace context. The response has been overwhelmingly favourable.

But having a comprehensive programme like Caring for Us (integrated into UN anti-discrimination policies) does not in itself guarantee a workplace free of stigma and discrimination for staff living with HIV. The fact that many people are simply afraid of being exposed to or contracting HIV or interacting with people living with HIV/AIDS is no surprise. As humans, we all fear things we don't know much about. In addition, the graphic images of PWHA as people who are starving, wasting away or look near death fuel stigma, fear and discrimination against people living with HIV/AIDS. Stigma as a result of these fears and images is harmful because it prompts people to act in ways that directly harm others by denying PWHA services, entitlements or social interaction in the workplace setting...

It is our hope that by continuing to tackle issues in our workplace and better supporting our own staff that we will not only increase our capacity the deliver better programming to our beneficiaries, but also to build more community advocates in all countries where we work.
Martina Clarke and Paul Sundry

3.3 Developing HIV/AIDS workplace policies in practice

There were many examples given of developing sound workplace policies that include access to treatment, maintaining confidentiality, creating a supportive environment for disclosure, and introducing widespread and/or peer education in the workplace. Whilst working for an international development agency operating in South Africa, Thoko Moyo contemplated the changes that would happen if one was to discover, for whatever reason, that one had contracted HIV, and from there his organisation developed programmes that were very effective in increasing awareness of HIV/AIDS amongst staff members. One of the events that had the greatest impact, again, was meeting a person living with HIV.

I saw just how important a role an organised workplace can play in creating awareness and supporting those affected by the virus... Many questions raced through the minds of my colleagues and I when thinking about: Would we be comfortable enough to tell anyone at work? Would they be able to cope with working with me if I had the virus and they knew about it, or would I be treated differently and judged because of my status? What were my rights as a member of staff? Would the company support me and my family, both financially and emotionally? Together with our headquarters in Washington we developed an in-house policy on HIV/AIDS, which dealt with issues such as the elimination of discrimination and stigma associated with HIV status or perceived status and encouraging staff to have voluntary testing...

We organised lunches every month with an AIDS theme – for me the one with the most impact was a meeting with a woman who was HIV-positive.

We organised lunches every month with an AIDS theme – for me the one with the most impact was a meeting with a woman who was HIV-positive. Until that day many people in the office had not knowingly met a person who was HIV-positive and her presence – a beautiful radiant woman who spoke positively and lived an active healthy life – shattered all the stereotypes of what a person who is HIV-positive looks like. She could have been anyone of us...

Our biggest success was to convince our headquarters that HIV/AIDS drugs should be discreetly and confidentially provided free to the staff. I chaired the HIV/AIDS committee for half a year, and in that time, despite what I think was a very well informed office, I never knew of anyone who actually took up counselling or told me that they had taken an AIDS test. But I certainly know that my own attitude towards the disease and people living with HIV changed for the better.
Thoko Moyo (South Africa)

David Mukasa from the Uganda Red Cross agreed that ignorance and fear underlie HIV-related stigma and acknowledged that stigma is not unique to HIV and AIDS; it has been documented with other infectious diseases, especially when the mode of transmission is perceived to be under the control of the individual. However, an inadequate understanding of the way transmission can take place in a work environment leads to fear of transmission through casual contact. He discussed the almost crippling effects on an individual of HIV-related stigma. He argued that employers have a responsibility to protect employees against discrimination, victimisation or harassment on the basis of HIV infection. Organisations must spell out very clearly their stand on equal employment opportunities irrespective of health status and respect for employee's confidentiality at all times.

HIV prevention efforts in a work environment depend on an atmosphere of openness, trust and respect for basic rights of employees. Unfortunately, stigma and discrimination undermine such efforts. This means that stigma and discrimination compromise the welfare and a safe, healthy work environment for employees.

Employers have a responsibility to protect employees against discrimination, victimisation or harassment on the basis of HIV infection.



Individuals' rights, such as those relating to confidentiality and access to benefits, should never be affected by one's HIV-positive status...

Information and education are vital components of an HIV-prevention programme that must take into account the different needs of male and female employees. It's so crucial to take into account the gender disparities and unique needs of either male or female employees.

From the conception of the idea to start up viable programmes, organisations must recognise the importance of involving employees and /or their representatives [or PWHA if available] in planning, and implementing awareness, education and counselling activities, to effectively address issues of stigma and discrimination, particularly as peer educators and counsellors. It may also be necessary to include the families of employees and the local community...

Practical measures to support behavioural change and risk management may call for the treatment of sexually transmitted infections, TB prophylactic services and distribution of both male and female condoms not only within your workplace but the community at large. By so doing you are dealing with and indeed stemming the root of stigma and discrimination.

David Mukasa (Uganda)

David suggested that a workplace HIV/AIDS policy should define an organisation's position and practices for preventing HIV transmission and for handling HIV infection among employees. The policy should provide guidelines to employers about their responsibilities and inform employees about their rights. He also touched on the importance of influencing leaders of organisations.

In order to address workplace stigma and discrimination effectively, we must better understand the causes, manifestations and consequences of work environment stigma and how these translate into discriminatory behaviours... The dynamics of stigma and discriminatory behaviour in workplaces (organisations) can be so detrimental, to the extent of being catalytic of spontaneous chain reactions spreading to other community set-ups and organisations. On the other hand, if HIV/AIDS programmes are put in place and success is registered, many organisations follow suit to share in the image and to emulate the positive trend...

The written HIV/AIDS policy approach acknowledges that HIV/AIDS is a major health issue and highlights the employer's commitment to addressing it in appropriate, responsible ways.

The major benefits of developing written HIV/AIDS policies as opposed to unwritten ones developed over time is that one can control or plan the results before an incident occurs. Another benefit is providing a framework for dealing with HIV/AIDS as an organisation /company. Written policies provide clarity and certainty about subjects like stigma and discrimination which people find confusing and at times unable to identify demarcations.

The written HIV/AIDS policy approach acknowledges that HIV/AIDS is a major health issue and highlights the employer's commitment to addressing it in appropriate, responsible ways. It is a unique condition in that it carries great social stigma, has a disproportionate effect on working age adults and in some areas affects a high proportion of the population. These policies acknowledge the potential impact of HIV/AIDS in the workplace.

Another thing is, if we are to get successful workplace HIV/AIDS programmes, we should always [consider] changing the leader, because if you do manage changing the leader, you can easily succeed in changing the organisation. Some programmes are failing because stigma and discrimination are so real and internally the leaders haven't changed to provide a favourable environment for implementing viable programmes. It's not easy to change the leaders. In fact, I've come to realise that leaders resist change as much as others do. The results? Unchanged leaders lead to unchanged organisations.

David Mukasa (Uganda)

The International Federation of Red Cross and Red Crescent Societies have been leaders in developing good workplace policy and practice on HIV/AIDS. The organisation set up a fund in 2003 to address the unprecedented challenge of HIV/AIDS to their work, in an effort to support staff and volunteers living with AIDS, by providing them access to antiretroviral therapy. It is estimated that the organisation may have 200,000 employees and volunteers living with HIV/AIDS internationally, posing a challenge to the survival of the organisation. The fund is seen to be an emergency measure until global efforts to increase access to treatment are successful.

3.4 GIPA in practice

Robert Baldwin, an openly HIV-positive employee of the Australian Red Cross and an advisor to the Asia Pacific Network of PLWHA (APN+) said he used to work for Australian government health institutions, "that provide top-level management support for people living with HIV as valuable employees and have good HIV workplace policies that emphasise the balance between individual rights and organisational responsibilities; these policies recognise that people with HIV are not the problem; the policies inform the organisations that they need to deal with these issues objectively, as they would with any other risk they face." He described his current work of putting the rhetoric of the GIPA principles into practice within



Positive employees and volunteers must not be treated as tokens. We have aspirations and needs, as anyone else does.

IFRC; but despite having an excellent workplace policy on HIV/AIDS, he still believes that the HIV-positive people within this massive organisation are largely invisible. He also recognised that although there are some positive individuals now employed within the region, often their employment does not have the wider institutional support and commitment of the organisation within which they are working.

We have had many successes, as can be seen by the increasing practical support to meet the needs that positive people have identified in the region, such as building support networks and treatment access, by National Societies (NS). I know of several positive people that have recently been employed by NS in meaningful jobs. However in many cases the employment of these positive people is in HIV specific jobs and does not seem to have any major impact on the organisation as a general entity. Also their employment is often reliant on the good will and understanding of individual managers. There appears to be minimal institutional support or commitment to their employment, such as an acknowledgment of the organisations duty of care, including long-term care and support.

As the largest humanitarian organisation in the world, where are the positive people within the Red Cross and Red Crescent Movement? I often hear figures of tens of thousands of HIV-positive staff and volunteers in this region. We cannot see them. This either means the figures are wrong and then we must ask why positive people are not involved in the Red Cross, or the figures are right and then we must ask why are they invisible...

The Red Cross and Red Crescent Movement, particularly the International Federation, has done some excellent policy and project implementation work in the area of GIPA. The HIV in the Workplace Directive (January 2003) is an excellent document that has as its objectives:

- 1. To protect the rights of employees who are infected or assumed to be infected with HIV.*
- 2. To encourage sensitivity and understanding among co-workers regarding HIV/AIDS issues.*
- 3. To provide managers at all levels with clear guidance on which they can base managerial decisions when confronted with issues relating to HIV/AIDS.*

Positive employees and volunteers must not be treated as tokens. We have aspirations and needs, as anyone else does. We want to learn, develop skills, have a career, earn money, and look after our loved ones and ourselves. We are not a charity but we do want to work with organisations to make life better for ourselves and other positive people.

Robert Baldwin (Australia)

3.5 The healthcare sector: caring for their own?

Dr Tesfamicael Ghebrehiwet described various evidence-based practices in tackling stigma in the workplace instigated by the International Council of Nurses (ICN). He discussed the ICN's 'zero tolerance' approach towards practices and attitudes that stigmatise and marginalise people on the basis of their HIV status. He also described a wide range of policies that ICN has developed over the years. Unfortunately, he says that where guidelines do exist, often there is little effort to disseminate them to all levels of health workers. He also stressed that strategies to address HIV-related stigma in the workplace will only be effective if partnerships are fostered between employers, health care professionals, the public, and people living with HIV.

As health care providers we confront the devastation of the HIV/AIDS pandemic each day. We routinely care for people living with HIV/AIDS and provide support to those affected by it. The courage, the expertise and the compassion of health care workers is frustrated by the lack of access to antiretroviral therapy (ARV), poor working conditions, lack of protective equipment and staff shortages. Health care workers are also frustrated by the rampant stigma and discrimination against people living with HIV and AIDS. Ironically health care workers who become infected with HIV are themselves subjected to stigma, discrimination or even ostracism by the public, their employers or even by their colleagues....

Interventions to address stigma in the workplace and all other settings will only work if effective partnerships are fostered between employers, health care professionals and the public, and with the active involvement of people infected and affected with HIV/AIDS.

Ethical codes and human rights declarations provide frameworks for fighting stigma and discrimination based on respect for the rights of people. Codes of ethics oblige health professionals to respect ethical principles, such as 'doing no harm' and 'doing good' to people in need of care. AIDS-related stigma and discrimination are clear violations of these codes... Professional ethical codes of conduct and human rights policies provide powerful guides for health care providers, based on respect for the rights of people. However, too often measures to enforce them are weak or



lacking and human rights of people living with HIV/AIDS are violated with impunity...

Where guidelines do exist, too often there is little effort to disseminate them to all levels of health workers. Development of a clear hospital policy on management of HIV-positive clients, reporting of adverse events such as needlestick injuries, and post exposure counselling and prophylaxis is required...

Interventions to address stigma in the workplace and all other settings will only work if effective partnerships are fostered between employers, health care professionals and the public, and with the active involvement of people infected and affected with HIV/AIDS.

Policies developed by ICN include:

- Policy on HIV-positive nurses in the workplace that calls for efforts to promote ethical practice that meets the needs and safety of patients.
- Position statement developed in 1987 that "deplores the stigma and marginalisation of people living with HIV/AIDS and called for competent, compassionate care"
- ICN Code of Ethics for Nurses affirms that ... "nursing care is unrestricted by considerations of age, colour, creed, culture, disability or illness..."
- Policy and guidelines for reducing the impact of HIV/AIDS on nursing and midwifery personnel and providing a framework for creating safer

work environments and for fighting stigma and discrimination

- Programmes to train health care providers which resulted in nurses implementing changes in practice that improved contact with patients, increased use of universal precautions, and improved nursing outreach services in the community, increased confidence to work effectively in HIV/AIDS care and prevention
- Guidelines addressing safer work environment
- Universal precautions
- Obligations of employers and managers
- Access to care and counselling

Dr Ghebrehwet suggested the following questions as drivers of policy:

- How can we translate policies and codes of conduct into action to underpin professional practice?
- How can health care workers and employers create a workplace that fosters care and compassion?
- How can we devise training programmes that go beyond information giving and result in change of attitude and behaviour of health care providers?
- How can access to ARVs for health care providers be improved? What is the impact on reducing HIV-related stigma in the workplace?
- How can we enhance the effectiveness of guidelines to create workplaces that are sensitive to people infected with and affected by HIV and AIDS?

Dr Tesfamichael Ghebrehwet

Interventions: specific points of concern

Previous discussions on the Stigma-AIDS eForum have provided insights into how HIV-related stigma and discrimination can be reduced. Here, however, the proposals have in many ways wider implications. It is in the world of work that PWHAs are required to engage with others; and interventions above provide specific insights into ways that this can be made more adept, and more consistent with a human rights-based framework.

Perhaps of most concern is the context of health care. Studies continue to suggest that here, HIV-related stigma and discrimination is strong – whether this also translates into similar behaviours towards HIV-positive co-workers is not clear yet.



4 The Private Sector

At the individual company level, lack of awareness and understanding can result in critical workplace conflict, disruption at managerial levels, and conflicts arising from unsuitable business responses.

UN agencies and international NGOs such as IFRC, that have made important contributions to the development of sound HIV/AIDS workplace policies, are not alone. The private sector has also begun to make important headway in changing stigmatising attitudes in the workplace, albeit often equally driven by economic imperatives.

4.1 The Asian Business Coalition

The Asian Business Coalition on AIDS voices the concerns of private companies about the impact of HIV/AIDS. The Coalition acknowledges that business can play a vital role in HIV/AIDS prevention and care, and that mobilising corporate resources in resource-constrained regions such as Asia may prevent further economic and social damage. The Coalition recommends developing HIV/AIDS workplace policies, workplace education and prevention programmes and introducing care and support programmes.

The growing HIV/AIDS pandemic is affecting more companies operating in developing markets every day. At the macro-economic level, HIV/AIDS destabilises markets and societies threatening occupational safety, undermining national investments, and resulting in decreased productivity and increased labour costs. At the individual company level, lack of awareness and understanding can result in critical workplace conflict, disruption at managerial levels, and conflicts arising from unsuitable business responses. In Thailand, for example, production line stoppages have occurred due to employees' fear of HIV transmission...

Companies wishing to protect their workplace from the negative economic and social effects of HIV/AIDS can immediately implement three measures.

1. HIV/AIDS workplace policy: Workplace policies aim to manage sensitive issues, such as confidentiality of medical

information and continuation of employment for HIV-positive staff, and assure that all testing and counselling services are performed on a voluntary rather than mandatory basis.

2. Education and prevention programmes: Education of employees about the transmission of HIV, prevention, non-discrimination towards HIV-positive colleagues, and availability of condoms and voluntary counselling and testing for staff are essential management tools to safeguard business interests.

3. Care and support measures: Many companies provide health care and support facilities for HIV-positive employees. These may be counselling services, compassionate workplace provisions (e.g. financial and insurance assistance and according time off for health related appointments) and/or medical treatment including access to anti-retroviral drugs.

The Asian Business Coalition on AIDS

Elsewhere, various private companies have begun to take action in the face of HIV/AIDS. A report on PepsiCo indicated plans to develop a policy on HIV/AIDS. PepsiCo will examine employee programmes and policies, and identify opportunities to fight the pandemic in communities where the company has operations.

Commenting on the decree in Indonesia (mentioned above in section 3.1), the national coordinator for HIV and AIDS for the International Labour Organisation (ILO), Tauvik Muhamad praised the move: "Conducting HIV tests will only burden companies as, besides being expensive, it does not guarantee that in the following days their workers will not be infected. It would be far cheaper for companies to campaign for the prevention and control of HIV/AIDS and organise education and training on the syndrome for their workers." Since last year, the ILO has cooperated with several organisations in providing awards for 30 companies



for their concern about HIV/AIDS. The problem in the region is acute: the ILO revealed that there were 90,000 to 130,000 people living with HIV/AIDS in Indonesia by the end of 2003. Due to many factors, such as a mobile workforce and a large sex industry (between seven and nine million clients per day, with a very low rate of condom use) they estimate that the number of people with HIV/AIDS could double by the end of 2004.

4.2 The need for 'human dignity' to shape policies

Tumaini Mbibo, a contributor from Tanzania suggested that 'human dignity' might be a "peaceful missile to destroy stigma and discrimination in the workplace". According to him, business leaders are becoming increasingly concerned about the likely financial impact of AIDS on their businesses and productivity, particularly due to absenteeism of workers; comparative studies of East African business have shown that absenteeism can account for as much as 25-54 per cent of company costs. The magnitude of the problem of HIV-related stigma and discrimination in the workplace was illustrated by the case of a Tanzanian entrepreneur who closed his business for two months in order to ensure an HIV-positive employee moved from the workplace. He suggested that apart from workplace policies, which might not be enforceable, appropriate legislation and peer education were keys to overcoming workplace discrimination and reducing the impact of HIV/AIDS on business.

The magnitude of the problem of HIV-related stigma and discrimination in the workplace was illustrated by the case of a Tanzanian entrepreneur who closed his business for two months in order to ensure an HIV-positive employee moved from the workplace.

4.3 Being prepared – the case in Mongolia

Amgaa Oyungerel, an HDN Key Correspondent from Mongolia said that HIV infection is expected to spread in Mongolia in the next years, and that the private sector will face problems similar to those in high prevalence regions. Amgaa argued strongly that the situation can be addressed by early mobilisation of positive forces from all levels of society including the private sector and advocating to employers about the benefits of instituting AIDS workplace prevention and awareness policies and programs from the

Amgaa suggested that peer education programmes have been particularly successful and that a public-private partnership is the key to an effective response.

outset. Amgaa suggested that peer education programmes have been particularly successful and that a public-private partnership is the key to an effective response.

For people living with HIV, as for many people, getting and maintaining decent and professionally rewarding employment is one of the most crucial life issues. It is a source of financial means, social recognition and psychological well-being.

Unpredictability of symptom onsets in the course of HIV disease, necessity to have frequent visits to clinics and follow long treatment schedules make people living with HIV/AIDS (PWHAs) more vulnerable to job loss and unemployment. For example, anti-retroviral (ARV) drug regimes and their side effects can lead to de facto disclosure of HIV status and many employers or co-workers cannot easily accommodate these needs...

Mongolia is a low HIV prevalence country with only few reported cases. However, rapid increase in HIV rates in the two neighbouring countries, Russia and China, high prevalence of sexually transmitted infections (STIs) and high-risk sexual behaviour in the general population increase the likelihood of extensive epidemic transmission in the country's near future. The country is undergoing a rapid transition to the market economy... structural changes across the country are shaping the profile and vulnerability to HIV of its workforce and youth. In this context, workplace HIV prevention interventions are an effective way to reduce the impact of the projected HIV epidemic.

At present, AIDS organisations are increasingly becoming aware of the pivotal importance of... targeting workforce in urban areas. For instance, the National AIDS Foundation, Mongolian Red Cross Society, Ministry of Defence and other non-profit and civil service organisations have successfully implemented peer education programmes in different occupational settings such as the military, transportation workers and petty traders...

It would be important for HIV/AIDS organisations in Mongolia to build a long-term relationship with newly emerging professional bodies and seize the opportunity when it arises. The policy of introducing HIV prevention and awareness programmes should then be supported with guidelines on how to implement them at individual company level.



Companies should also be encouraged to review their existing human resource recruitment, work condition and benefit policies with the perspective of potential situations to accommodate needs of their HIV-positive employees. In addition, as the Labour Law of Mongolia requires certain industries with high occupational health concerns to carry out routine health check ups and blood testing of all of their employees, it is important that companies review their relevant internal procedures to prevent any potential abuse of HIV testing without employee's consent.

These responses at company and sectoral level should be supported with comprehensive national policies and strategies that include educating key policy makers, developing codes of practice to support implementation of these policies. According to the Labour Law of Mongolia, all employers should provide equal employment opportunities for people regardless of their gender, age, ethnicity or state of disability...

The private sector with its strengths in human resource training, logistics, marketing and untapped sense of social responsibility can contribute a great deal to a country's response to HIV/AIDS. Private-public partnership is vital for Mongolia and it should keep vigilance in fighting stigma and discrimination against PWHA in all aspects of workplace.

Amгаа Oyungerel (Mongolia)

Effective HIV and AIDS workplace programmes are indeed long-term human resource investments. It is hopeful and inspiring that a country such as Mongolia, currently with low infection rates but vulnerable to an HIV epidemic, is preparing and developing programmes that will mitigate the impact of the HIV and reduce or eradicate the stigma of AIDS, before it becomes embedded in people's psyche. These programmes will help to create a supportive working environment for PWHA and to reduce risk-associated sexual behaviour among young working people.

Contributions of the private sector: specific points of concern

The private sector, as well as the NGOs discussed above, clearly have a responsibility to maintain a safe environment within which PWHA can work. Coalitions such as the Asian Business Coalition will be instrumental in shaping the responses of employers to HIV-positive employees. There remain many unanswered questions, however. Who can regulate employers and their HIV-related policies? To depend on good will is surely inadequate, and it is for governments to ensure that appropriate policies and legislation are in place.



5 Conclusion

This discussion revealed key issues shaping the context of HIV-related stigma and discrimination in the workplace. As a discussion, it meshed with previous topics – many elements of self-stigma and disclosure also apply to the workplace, and the summary above should be seen as complementing previous documents in the current series.

In the workplace and other institutional settings, PWHA are forced into an interface with others, and the examples of good practice, and enlightened interventions discussed above suggest there are positive steps that can be taken. Continuing gaps in legislation and policy do raise serious questions, however, about the commitment of some governments and organisations to take steps in this area.

From the points made at the close of each section of this document, there are a number of key recommendations that should be considered by all those involved in the HIV/AIDS response in order to help tackle stigma in the workplace and institutions:

- 1** The workplace exposes PWHA to distinct manifestations of stigma and discrimination – appropriate policies must be in place to protect the livelihood, security and support of affected people.
- 2** Models of good practice should be used to inform all initiatives, and in particular the provision of information, and involvement of affected people can have a significant impact in the workplace.
- 3** In line with broader initiatives, the need for a human-rights based approach is paramount, embedded in robust employment legislation.
- 4** Pressure must be brought on both the public and private sectors to set specific targets for developing appropriate policies.



Appendix 1:

Stigma and discrimination in the workplace and institutions – Sources and references

The following is the list of publications referred to in this report. It also serves as a list for further suggested reading on HIV-related stigma and discrimination in the workplace and institutions.

India: HIV and AIDS-related Discrimination, Stigmatization and Denial. Best Practice Collection. UNAIDS, 2001.

Greater Involvement of PLHA in NGO Service Delivery: Findings from a Four-Country Study. Population Council/ Horizons, 2002.

Code of Practice on HIV/AIDS and the World of Work. International Labour Office, 2001.

AIDS Discrimination in Asia. Asia Pacific Network of people living with HIV/AIDS, 2004. (Online at: www.gnpplus.net/regions/asiapac.html)

Bharat S. AIDS in the employment sector in India: A vicious cycle of silence and denial. *XIII International AIDS Conference, South Africa*, 2000, Ab TuPeD3490.

Bharat S, Aggleton P. Facing the challenge: household responses to HIV/AIDS in Mumbai, India. *AIDS Care* 1999, 11: 31-44.

Busza J. Promoting the positive: responses to stigma and discrimination in Southeast Asia. *AIDS Care* 2001, 13: 441-456.

Cornu C, Ouedraogo A, Sankara A, et al. How do people living with HIV/AIDS become successfully involved in the community-based organizations that serve them? *XIII International AIDS Conference, South Africa*, 2000. Ab TuPeE3928.

Managing HIV in the Workplace. Global Business Coalition on HIV/AIDS. (Online at: www.businessfightsaids.org/wpp_tool.asp)

Greater Involvement of PLHA in NGO Service Delivery: Findings from a Four Country Study. Population Council/ Horizons, 2002.

Draft Code of Good Practice for NGOs responding to HIV/AIDS. International Federation of Red Cross and Red Crescent Societies. (Online at: www.ifrc.org/what/health/hivaids/code/)

Code of Practice on HIV/AIDS. International Labour Organization. (Online at: www.ilo.org/public/english/protection/trav/aids/code/codemain.htm)

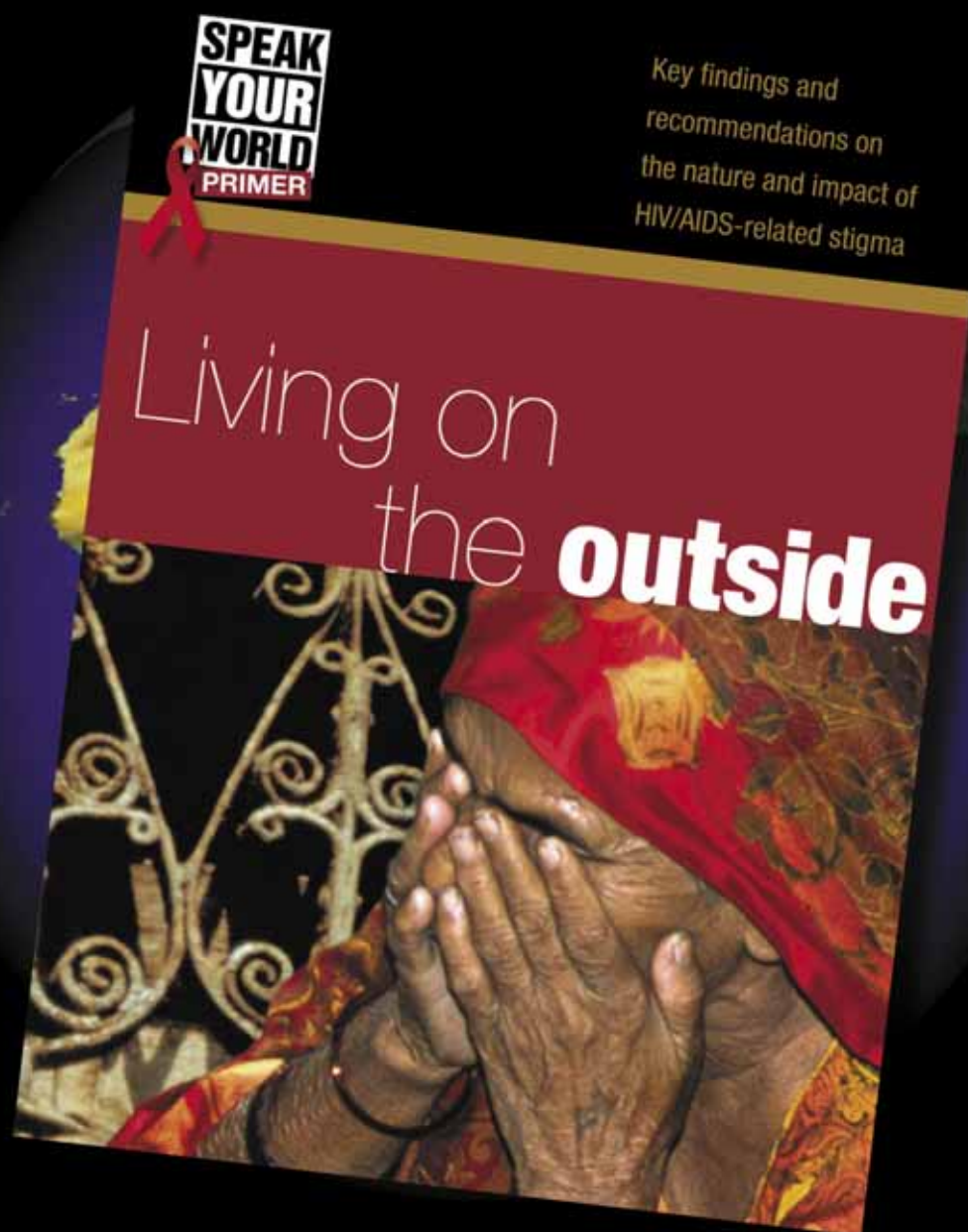
Positive, Engaged, Involved - The Participation of People Living with HIV/AIDS (PLHA) in Community-based Organizations. Population Council / Horizons, 1999.

Literature Review - Challenging HIV-Related Stigma and Discrimination in Southeast Asia; Past Successes and Future Priorities. Population Council / Horizons, 1999. (Online at: www.popcouncil.org/pdfs/horizons_paper.pdf)

From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA). Best Practice Collection. UNAIDS, 1999. (Online at: www.unaids.org)

Enhancing the Greater Involvement of People Living With or Affected by HIV/AIDS (GIPA) in sub-Saharan Africa. UNAIDS. 2000. (Online at: www.unaids.org)

covering your world



WHO/P Viroc (Modified by P Short)

Speak Your World Primer comprising key findings and recommendations on the nature and impact of HIV/AIDS-related stigma

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A vigorous response to health- and development-related issues requires a means of supporting local participation, accountability and a sense of stakeholder ownership. It needs to be more reflective, inclusive and cohesive than the top-down responses to date.

Individuals, communities and organisations must be able to learn from the actions and experiences of others, and adapt and apply these lessons in their own contexts.

Current health- and development-related discourses are mostly exclusive, take place on different and separated levels, among isolated sectors, and only rarely encourage direct civil society participation in debate, dialogue or policy-setting.

HDN eForums provide a platform for thousands of people and civil society

organisations at all levels to connect with each other and to share lessons. They facilitate a bottom-up approach to information gathering, and view any given topic from several different perspectives in order to validate its significance. The eForums also provide a unique learning opportunity for members.

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