



**HIV**  
**AUSTRALIA**

**Stigma and discrimination**

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## **AFAO's aims are to:**

- Advocate on behalf of its members at the Federal level, thereby providing the HIV/AIDS community with a national voice;
- Stop the transmission of HIV by educating the community about HIV/AIDS, especially those whose behaviour may place them at high risk;
- Assist its members to provide material, emotional and social support to people living with HIV/AIDS;
- Develop and formulate policy on HIV/AIDS issues;
- Collect and disseminate information for its members;
- Represent its members at national and international forums; and
- Promote medical, scientific and social research into HIV/AIDS and its effects.

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AFAO is the peak non-government organisation representing Australia's community-based response to the epidemic of HIV/AIDS. AFAO's members are the state and territory AIDS councils, the National Association of People Living with HIV/AIDS, the Australian Injecting and Illicit Drug Users League, Scarlet Alliance and the Anwernekenhe National Alliance.

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# HIV AUSTRALIA

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# AUSTRALIAN NEWS

## Australian success could save people with HIV worldwide

Scientists working out of Melbourne's Burnet Institute announced in June the development of a simple diagnostic test which would help or even save the lives of many people living with HIV in developing countries. Using a blood sample from a pricked finger, the test is similar to a pregnancy test but instead shows the count of CD4 T-cells in the blood. Designed for field use in remote settings, the new test enables patients at the point of care to find out within 30 minutes if they should begin antiretroviral treatment, without any laboratory equipment being required.

Currently, CD4 counts can be extremely expensive for people living with HIV in developing countries. They are required often to pay for the test themselves, at times at inflated prices set by both private and public hospitals. Many countries have only a few CD4 count machines, or even one. The machines are often broken. They require laboratory staff and an adequate supply of chemicals.

So this breakthrough could have significant benefits for people with HIV. The majority of patients in developing countries start antiretroviral therapy based on symptoms alone. Research shows that if HIV patients wait until they are sick to start treatment, they have a much poorer outcome than if treatment were started based on a CD4 count. Meanwhile, some countries use CD4 counts to ascertain when people with HIV can access treatment. Furthermore, this test will allow people with HIV to more

easily monitor their treatment to see if in fact their current regimen is working.

Professor Suzanne Crowe, Associate Professor David Anderson and senior scientist Mary Garcia lead a team at Burnet with expertise in diagnostic test development. Crowe explained, 'This is a unique test. There is nothing available that can test the immune system like this without laboratory facilities. It can be taken into remote villages and performed on the spot.'

The development of the test was funded by the Bill and Melinda Gates Foundation and is undergoing clinical studies in the United States, Britain and Australia to ensure it produces a reliable result. If the results of the studies are successful, the test could be produced and in use as soon as by the end of next year at a cost of \$2 a test.

Professor Brendan Crabb, Director and CEO of the Burnet Institute said, 'I am very proud to announce the Burnet Institute's creation of the CD4 rapid test that has the potential for such a hugely positive impact on people with living with HIV across the world.'

## Launch of National STI Prevention Program

On 29 May 2009, Nicola Roxon, Minister for Health and Ageing launched the new National STI Prevention Program. The aim of the program is to reduce the prevalence of sexually transmitted infections among Australians aged 15–29 years.

The theme of the campaign is: 'STIs are spreading fast – always use a condom'. It also includes information about the transmission, symptoms, treatment and prevention of STIs, and

encourages young people who have had unprotected sex to see a doctor about getting tested. Research for the campaign found that young Australians aged 16 to 29 are not well informed about the benefits of condom use.

The media campaign includes advertising on radio, magazines, outdoor billboards and the Internet. It will be supported by other activities including use of the internet, and an Indigenous partnership program.

## ACON CEO resigns

ACON Chief Executive Officer Stevie Clayton announced her resignation in July, after nine years at the helm of Australia's largest community-based GLBT health and HIV organisation. Ms Clayton oversaw the organisation's transition from the AIDS Council of NSW to ACON Health, a GLBT community health service.

Ms Clayton was awarded a Medal of the Order of Australia for her work in 2003. ACON President Mark Orr paid tribute to her, saying, 'On behalf of the members and the board of ACON, I would like to thank Stevie for her hard work, dedication and commitment to ACON'. AFAO CEO Don Baxter called Clayton a 'feisty' and 'politically astute' leader. 'Her energy and forceful style has kept ACON as one of the top three HIV community organisations in the world', he said.

Stevie said, 'This is one of the most difficult decisions I have ever had to make. I love ACON with a passion ... and it feels like getting a divorce while you're still in love'. She remained tight-lipped about her future, saying, 'I'm studying law part-time, so I'm going to keep doing that, but beyond that I really don't know. But I intend to spend a lot more time with my partner. Aside from that, we'll see where life takes me!'



## Got something to say?

**Your views are important to the success of this publication.**

*HIV Australia* publishes letters and contributions from readers. If you want to respond to something you have read here, or have an idea for an article, please write to us at: [editor@afao.org.au](mailto:editor@afao.org.au)

# ICAAP UPDATE

## Indonesian President opens Asia-Pacific AIDS Conference in Bali

Indonesian President Susilo Bambang Yudhoyono opened the 9th International Congress on AIDS in Asia and the Pacific (ICAAP) in Bali on 9 August. With the theme 'Empowering People, Strengthening Networks', the conference brought together over 4,000 representatives from around Asia and the Pacific region. President Yudhoyono emphasised the importance of leadership in responding to the epidemic. 'Without leadership, the fight against AIDS becomes sporadic, reactive, without focus, lacking resources and will eventually lose their sting', he said.

President Yudhoyono welcomed delegates to the conference. 'It is my hope that greater collaboration and partnerships will arise from this important conference. After all, it is only by "empowering people and strengthening networks" – precisely the theme of our conference today – that we can bring the HIV epidemic under control,' he said.

UNAIDS Asia Pacific Regional Director Prasada Rao said that there are now over five million people with HIV in Asia and the Pacific, with at least one million unable to access anti-retroviral treatment.

In a message to the Congress, UNAIDS Executive Director, Michel

Sidibé said some countries in the Asia Pacific were beginning to see success in their efforts to reverse the spread of HIV, but not enough to break the trajectory of the epidemic.

'We must transform the AIDS response in Asia so that it works for people – especially for people who have been marginalised and without a voice', he said. 'This means protecting sex workers, men who have sex with men, transgender, injecting drug users and their intimate partners.'

## AFAO and global forum agree: disaster inevitable

Epidemiological data on HIV transmission released at the ICAAP Conference shows the virus sweeping unchecked through the big cities of the region, with 200 men who have sex with men (MSM) a day becoming infected.

The conference heard about a staggeringly high incidence of HIV infection, particularly among young men in Bangkok, Yangon (formerly Rangoon) and amongst transgender people in Indonesia. Nearly 30 percent of men who have sex with men in Bangkok and Yangon are HIV positive and many other Asian cities have rates of 5–10 percent and growing rapidly.

AFAO Executive Director Don Baxter, who is also a Co-Chair of the Global Forum on MSM and HIV, described the situation in

Bangkok and Yangon as disasters and the situation in all other major Asian cities as at crisis point. 'Every day of delay in responding to this accelerating health crisis results in another 200 men being infected with HIV in the region. Every year that we delay intervention another 73,000 new infections occur.'

'The window for effective prevention is still open, but it is closing rapidly. Many Asian cities are approaching take-off point for the disaster that has already occurred in Bangkok and Yangon. Active intervention and investment put in place now will avoid exponential HIV treatment costs within five years. The governments of Asia, along with the major donor countries, need to scale-up HIV prevention programs and investment dramatically to save lives.'

Mr Baxter called on AusAID to adjust its funding priorities immediately, noting that Australia's current investment in Asia Pacific HIV prevention involved contributing more than \$60 million over five years with injecting drug use, compared to less than \$1 million for HIV prevention among gay and bisexual men.

'These figures are totally out of proportion to the epidemiological reality that confronts Asia and the Pacific. Male-to-male sex will contribute more than 50 percent of new infections in the Asia Pacific by 2020 unless AusAID acts quickly on its recent scoping study and, along with other donors, invests in programs immediately – before the window of opportunity slams shut,' Mr Baxter said.

## TREATMENT UPDATE

### Sculptra approved for PBS

From 1 September, Sculptra, a treatment for facial wasting, will be subsidised under the Pharmaceutical Benefits Scheme (PBS). This move has been widely welcomed by HIV agencies.

As many as one in eight people with HIV who are taking anti-retroviral treatments suffer from Lipoatrophy as a side effect. Lipoatrophy is the technical

term for the loss or 'wasting' of fat from the face and other areas of the body such as the buttocks, upper arms, legs and thighs. Facial lipoatrophy can lead to sunken cheeks, hollow temples and loss of fat around the nose, mouth and eyes. Facial lipoatrophy is frequently a cause of depression and anxiety for people living with HIV.

Sculptra contains poly-L-lactic acid (PLLA), sodium carboxymethylcellulose and mannitol. PLLA is non-toxic and has been widely used in products such as resorbable sutures. It is injected into the face and stimulates the body's natural collagen production, gradually restoring

lost facial volume. The most common side-effects associated with Sculptra are injection-related, such as bleeding pain, local redness, bruising and swelling.

Sculptra can only be administered by doctors or surgeons who have completed specific training. Listing of Sculptra on the PBS means that each prescription will cost a maximum of \$32.50 for people not holding a health concession card. At this stage, the procedure for injecting Sculptra is not covered by Medicare and therefore costs vary between practitioners.

*See page 50 for more Treatment Briefs.*



# NEWS FROM THE ASIA PACIFIC

## Funds for tackling HIV and STIs in the Pacific Islands

The Pacific Islands HIV and STI Response Fund, supported by Australia and New Zealand announced in the first round of their grants that they will award a total of more than AUD \$9 million to 44 successful applicants. Recipients include national HIV programs and civil society organisations from 11 Pacific Island countries and territories, as well as non-government organisations (NGOs) operating at a regional level, development partners and UN agencies. All projects are aligned with the Pacific Regional Strategy on HIV and other STIs and national HIV strategic plans, in an ongoing bid to coordinate efforts and improve service delivery.

Launched in 2008, the Pacific Islands HIV and STI Response Fund is managed by the Secretariat of the Pacific Community (SPC) and overseen by an independent fund committee. Response Fund grants are for three-year projects and cover activities such as regional training on testing and counselling, advocacy for improved human rights legislation, HIV in the workplace, condom distribution and strengthening capacity of national laboratories to diagnose HIV.

The emerging trend of increased incidence of STIs in the Pacific has been a cause of concern as STIs mean both increased susceptibility to HIV infection and increased infectivity among those who are HIV-positive, as existence of an STI is also a marker for unprotected sex and high levels of sexual activity.

## India: Court decides on rights

Indian laws criminalising sex between men have been found unconstitutional, in a key decision by the Delhi High Court.

Section 377 of India's penal code describe homosexual intercourse as 'carnal intercourse against the order of nature', and impose a 10-year jail term for offenders. The law dates back to the days of the British Raj.

The Delhi High Court declared the laws a violation of 'fundamental rights' and unconstitutional. The Court recommended that the Indian Government amend section 377 in accordance with its ruling. It is not clear whether the Government will appeal the decision. Law Minister M. Veerappa Moily responded cautiously, saying he would study the judgment before commenting.

The ruling is a major victory for India's gay rights movement, which has campaigned for homosexuality to be decriminalised. 'We are elated,' said activist and lawyer Aditya Bandopadhyay. 'I think what now happens is that a lot of our fundamental rights and civic rights which were denied to us can now be reclaimed by us'.

The decision drew angry reactions from religious leaders. 'This is absolutely wrong', said Muslim leader Ahmed Bukhari, the Imam of Delhi's Jama Mosque. 'If the Government (attempts) to scrap Section 377, we will oppose it strongly.'

However, the decision has been welcomed by UNAIDS. Michael Sidibé, Executive Director of UNAIDS, said that the criminalisation of homosexuality 'drives people underground making it much harder to reach them with prevention, treatment and care services'.

## India: training new healthcare workers on HIV

One of the key problems of treating and caring for people living with HIV in Asia is the lack of qualified

healthcare workers. A program launched by the AIDS Healthcare Foundation (AHF) and Indira Gandhi National Open University (IGNOU) last year aimed to address this by creating a new category of healthcare workers. In June, 24 students graduated as the first recipients of the newly created HIV Medics degree.

The HIV medics are para-professional health care workers trained to assist clinicians in the provision of antiretroviral therapy (ART) for people living with HIV.

The HIV Medics will act as first line of support to doctors and nurses, and help in providing psychological support to patients. They are trained to draw blood, dispense medications and provide medication adherence counselling and HIV testing. They will provide initial patient screenings, complete patient histories and refer patients to physicians for physical examination.

It is intended that shifting these tasks to HIV Medics will free physicians, nurses and other healthcare professionals to concentrate on other areas to improve quality of care for HIV patients

The students received a rigorous three-months training at a School of Social Work as well as clinical skill training at various community care homes in Delhi.

The HIV Medic training is designed for students with no prior medical training or experience and with a high school certificate and included PLHIV among their ranks.

'With the dearth of human resource in healthcare sector in India, the IGNOU plans to expand the course on a large basis,' said IGNOU Pro-Vice chancellor Om Prakash Mishra.



# INTERNATIONAL NEWS

## Global Financial Crisis threatens treatment

Aidsmap reports that a new World Bank survey shows that up to 1.7 million people in Africa, Eastern Europe, the Caribbean and Asia are at risk of antiretroviral treatment interruption due to the global financial downturn. The World Bank stated unequivocally: 'The international community is obligated to continue to support the people it has placed on ART ... The international community has made an unambiguous commitment towards universal access to treatment for people with HIV who need it.'

The implications of interrupted treatment could include greater long-term costs due to higher rates of transmission, more TB cases and larger numbers requiring expensive second-line drugs for both HIV and TB. Surveying national AIDS programs in 69 countries in March 2009, the World Bank calculated that continuity of treatment could be threatened for around 70 percent of people currently on treatment in eastern and southern Africa. Around 50 percent in the Asia-Pacific region, 35 percent in the Caribbean and 25 percent in Eastern Europe and Central Asia could also be affected.

The report notes the fragility of financing arrangements for countries largely dependent on external aid for their HIV programs. Eighteen of 47 countries that provided data said that grants from the Global Fund to Fight AIDS, TB and Malaria end in 2009 or 2010. The Global Fund faces a funding shortfall of \$4 billion in 2010, director Professor Michel Kazatchkine said recently. The Global Fund has postponed its Round 9 funding allocations until November 2009 in order to allow more

time to mobilise funding. Middle-income countries appear less vulnerable, with no countries in Latin America anticipating a reduced ability to pay for antiretroviral treatment during the next year.

Thirty-four countries representing 75 percent of people living with HIV said that they expected prevention programs to be negatively affected, and national AIDS programs anticipated greater impact on prevention than treatment, with prevention targeting marginalised groups such as men who have sex with men and injecting drug users at greatest risk, according to respondents.

The cost of even minor treatment interruptions are high: up to 50 percent of people taking first-line treatment may need a second-line regimen if their treatment is interrupted for more than 15 days, due to the development of drug resistance.

In the meantime, reports have emerged that between January 2008 and April 2009, The Bill & Melinda Gates Foundation saw its assets drop from \$39 billion to \$27.5 billion. While they won't be cutting distributions this year, they will slow the growth of the Foundation. Although the Gates Foundation primarily works through the Global Fund for its contributions to HIV, it also supports many important HIV organisations and programs around the world.

## New study on the effects of stigma

High levels of stigma are experienced by people with HIV. This is consistently associated with lack of social support, poor physical and mental health, poverty, and younger age, according to the results of a meta-analysis published in the June edition of *AIDS Care*.

Stigma has been associated with HIV since the beginnings of the epidemic and is experienced by people with HIV in different contexts in a variety of ways. HIV-positive people are often blamed for their infection, on occasion even by healthcare providers. HIV also disproportionately affects groups that are already stigmatised, such as gay men, injecting drug users, women who have been raped and refugee and migrant populations.

Studies examining HIV-related stigma have varied in their sample size and population, measures of stigma, data collection and statistical analysis. This has made it difficult to compare findings or generalise them to wider populations of people living with HIV.

Investigators therefore conducted a meta-analysis of recently published studies that measured HIV-related stigma. A total of 24 studies published in peer-reviewed journals since 2000 were included in this analysis. These studies involved a total of 5,600 HIV-positive individuals from diverse backgrounds.

Although there was considerable variability in the way the included studies assessed individuals' experiences of stigma and their health and well-being, the investigators nevertheless found that 'high stigma levels were consistently and significantly associated with lack of social support, poor physical health, poor mental health, lower income and younger age.' Adequate social support and good mental health were both associated with lower levels of reported stigma.

The authors recommend that 'effective interventions to challenge HIV-related stigma should operate on multiple levels and target several populations.' Wide-ranging structural interventions are also needed, and the authors suggest these should provide legal protection from stigma and discrimination as well as addressing poverty and disadvantage.

## Reference

Logie C. et al. (2009) 'Meta-analysis of health and demographic correlates of stigma towards people living with HIV', *AIDS Care*, 21: 742-53.



# International Whores Day: sex workers against stigma and discrimination

By Finn O'Keefe

June 2 2009 marked the 34th Anniversary of International Whores Day. To commemorate the occasion, Scarlet Alliance – the Australian Sex Workers Association – held a mass protest outside Parliament House in Sydney.

International Whores Day is said to have its origins in Lyon, France in 1975, when a group of local sex workers staged a protest against police for failure to investigate or prosecute crimes against them. The police reportedly responded to this action by threatening to take their children away.

The injustice of the situation seemed so blatant that it encouraged many townspeople to join with the sex workers in protest. The upshot of this was police couldn't tell who was, and who wasn't a sex worker. International Whores Day commemorates this historic action and is considered to be one of the formative moments of the sex workers' rights movement.

Fast forward almost 35 years, and sex workers around the world are still facing discrimination. Demonstrators in Sydney wore red and carried red umbrellas as a mark of solidarity with other sex workers. Speakers rallied against the discrimination and stigma that they routinely face from financial

institutions, lenders and local councils, just to name a few.

One key issue that speakers raised was about discriminatory practices that exist in advertising which see sex workers disproportionately charged for placing ads compared with other tradespeople who use newspapers to promote goods and services. Demonstrators demanded protection under anti-discrimination and equal opportunity laws. As sex worker Ivy McIntosh says, 'I'm paying too much for a measly two inches. Sex work is legal in NSW. Why am I charged hundreds of dollars to advertise in local papers when other trade occupations are charged less than \$100?'

Speakers highlighted other forms of injustice: 'Sex workers face discrimination when seeking financial and insurance services. These services are taken for granted by the general communities but are either not available to sex workers or come at inflated prices', Elena Jeffreys, President of Scarlet Alliance, said.

'Discrimination against sex workers by local councils excludes us from our rights as citizens and rate-payers', said Saul Isbister, sex worker and Sex Services Premises Planning Advisory Panel Member. 'However, the Guidelines for Local Councils recommend a mature evidence-based approach that supports the rights of sex workers.'

Janelle Fawkes, CEO of Scarlet Alliance, said, 'Anti-discrimination laws protect sex workers from discrimination; however sex workers are only included in two states. Sex workers are calling for anti-discrimination protection throughout Australia.' Fawkes concluded: 'Systemic discrimination of this kind by financial, insurance, advertising businesses and local government cannot be allowed to continue.'

## Reference

Hexplusive Blog <http://www.hexpletive.com/2009/05/international-whores-day-red-umbrella.html> (accessed 17 July 2009)

**Finn O'Keefe is one of the Editors of HIV Australia and a Policy Analyst at AFAO.**



# Stigmatisation, discrimination: a health and human rights perspective

By Daniel Tarantola

Stigmatisation and discrimination have in common their nefarious effects on people's physical, mental and social well being.

If HIV is the root cause of AIDS, stigmatisation and discrimination are the root causes of the AIDS pandemic. Stigmatisation and discrimination have in common their nefarious effects on people's physical, mental and social well being. At a time when financial resources and political commitment to bring the HIV epidemics under control are mounting, together they constitute the greatest impediments to open access to services, to solidarity and social harmony.

I have attended many HIV strategic meetings in settings across the world and invariably, in all situations, all epidemiological, cultural and political environments, stigma and discrimination top the list of obstacles that have to be addressed to respond to HIV. Prevention interventions have proven effective in reducing risk behaviours and the spread of the virus, for example through safer sex promotion, community organisation and mobilisation, harm reduction

in the context of drug use, or the quasi-elimination of mother-to-child transmission of HIV. Yet, the scaling-up of these interventions and even their ultimate effectiveness is constrained by the isolation in which individuals and communities may be forced as a result of stigma and discrimination.

New opportunities for greater access to HIV treatment and care have been

*continues overleaf*

created by the plummeting of the cost of medicines, the emergence of simpler therapies and drug formulations, the significant flow of resources and a commitment on the part of health systems and communities to make treatment options real for people who need them. Yet progress is slow, access targets are not met and, invariably, stigmatisation and discrimination keep the majority of people who need treatment away from life-saving services, technologies and sources of support. Stigma and discrimination have become so commonly mentioned as the causes of our collective failure to match needs, demands and resources that they are frequently referred to as 'S&D', as if it were a disease, a corporation, or a permanent entity with its own existence, and ineluctable power. Coincidentally, in the English language, S&D stands for Search and Destroy ... a sombre analogy ...

Abundant empirical and scientific evidence shows that stigmatisation and discrimination are bad for HIV, bad for public health and bad for human rights. On the flip side, they also have in common the ways in which they have catalysed communities coming together

to respond to HIV as people who have suffered, and continue to suffer from stigma and discrimination, have learned to create their own counter-power and counter-support groups against social threats to their own existence and survival. The rising empowerment of communities affected by HIV; the growing role civil society is playing in the response to the epidemics; and the increasing recognition by governments globally that the involvement of communities is critical to an effective response: all of these are testimony to the fact that stigma and discrimination can be exposed, challenged and mitigated, if not fully overcome.

#### **Commonalities; differences**

So, let us ask ourselves first, what is behind these two words.

**Stigmatisation** is a social practice that brands an individual or group in negative ways and devalues them because of some actual or perceived characteristic. In the context of the pandemic, stigma has occurred because of HIV status, associated behaviors, personal or family history, community affiliation or social characteristics.

Stigmatisation manifests itself through

blame, shame, judgment, insult, rumours, assumptions, derision and it creates an environment conducive to discrimination. Stigma should not be perceived as a mild form of discrimination: it is the forerunner thereof and takes place when people do nasty things to each other because of fear and ignorance.

Combating stigma is through information, education, questioning community attitudes, explicating and overcoming cultural or religious barriers to inclusion, and an openness to act in concert to alleviate the harms caused by stigmatisation. The role of the World AIDS Campaigns and ongoing communication efforts through civil society networks, the media, in schools, or in places of worship go a long way towards giving HIV a human face, creating mutual empathy, and instating or restating social harmony.

**Discrimination** manifests itself through neglect, isolation, rejection, harassment and abuse perpetrated by the state, by those acting on its behalf and by non-state actors in their individual or collective capacity. Discrimination is borne out of the compelling human obsession for differentiation and fear of the unknown. The primary purpose of differentiation is to make a complex universe more understandable and seemingly more manageable.

But when differences are not understood, they may be perceived as threats and generate fear. Herd behaviour lends itself to containment mechanisms which may range from avoidance to isolation, exclusion, persecution and elimination. And if the purpose of civilisation is to codify and organize herd behaviours, discrimination, then, is both a violation of human rights and a failure of civilisation.

Stigma and discrimination have become so commonly mentioned as the causes of our collective failure to match needs, demands and resources that they are frequently referred to as 'S&D', as if it were a disease, a corporation, or a permanent entity with its own existence, and ineluctable power.

Combating discrimination requires remaining alert to the multifarious forms through which it is expressed. The empowerment of people living with HIV and communities exposed to discrimination constitutes both best public health practice and progress in human rights terms. This begins with awareness about human rights under national and international law as well as familiarity with public health best practice. The responses to HIV in countries like Malaysia have created much needed space for civil society to play an active role in this response. Enhanced education of service providers about a rights-based approach to HIV, fair law enforcement, just policies and responsive legislation can transform the participation of affected communities into empowerment for the benefit of public health.

### Focusing on discrimination

Combating stigma and discrimination requires both recognising their close interaction and distinguishing their differences. In short, to combat stigmatisation requires eliminating its roots in order to alter its manifestations. To combat discrimination is primarily to recognise and eliminate its manifestations in order to uproot it.

I will focus most of this article on discrimination as it represents the most tangible infringements on people's human right to be treated equally and fairly in the context of HIV. It is a human rights violation and, from a purely instrumental perspective, connotes bad public health practice.

**HIV-related discrimination is both pervasive and invasive.** Pervasive, it spreads across populations as a result of ignorance, misconception, stereotyping and stigmatisation. Pervasive

discrimination is perpetrated against people living with HIV, denying them the right to education, employment, housing or free movement. It is perpetrated against migrant workers, prisoners and more generally, people whose behaviours or lifestyles evoke a risk of HIV infection. The pervasive nature of HIV-related discrimination stems from perceived linkages between a virus against which there are no vaccines and only imperfect treatments, and concerns about socially, culturally and legally reprobated behaviours, such as substance use, sex between men, sex work or sex out of wedlock that cast an aura of societal disapproval around those who are seen as both self-inflicted victims and sources of infection.

By association, then, discrimination extends from people who suffer from HIV-related illnesses to carriers of HIV, to those who engage in injecting drug use, same-sex sex, or sex work, and more broadly to those who are regarded as likely to belong or be connected to these communities, to those who care for them and to those, migrants for example, who because of fear and ignorance are assumed to harbour and spread HIV.

Discrimination is **invasive**: from its roots to its ultimate outcome, it deeply affects the lives of people subjected to discrimination by generating discomfort, humiliation, fear, denial of equal treatment and harmful physical, mental and social impacts.

Discrimination can result in exclusion as a result of policies, laws or practices. It may also result in self-exclusion whereby people who are the subjects of discrimination avoid situations where their rights are denied and their dignity offended. This happens when people living with HIV or wanting to know their HIV status do not seek treatments or stay away from testing services by fear of discrimination.

The invasive nature of discrimination in the world of HIV encompasses the discomfort that affects service providers, including law enforcement personnel and health professionals, when they are faced with a virus they do not fully comprehend, an infection

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The empowerment of people living with HIV and communities exposed to discrimination constitutes both best public health practice and progress in human rights terms.



# Bad blood? Gay men, the Red Cross and blood donation

By Abigail Groves

The Red Cross welcomed the Tribunal's decision, insisting that its policies are based on infection risk and testing limitations rather than the sexual preferences of donors.

A long-running discrimination complaint against the Australian Red Cross Blood Service (ARCBS) by Tasmanian gay man Michael Cain was dismissed last month. In 2004 Michael Cain's blood was refused by the ARCBS in Launceston after he answered 'yes' to a screening question about gay sex.

But nearly five years later, after a lengthy legal process, the Tasmanian Anti-Discrimination Tribunal dismissed Cain's complaint of discrimination. The Tribunal's decision effectively re-affirmed the ARCBS policy of not accepting blood donations from men who have had sex with men in the previous 12 months.

The ARCBS welcomed the Tribunal's decision, insisting that its policies are based on infection risk and testing limitations rather than the sexual preferences of donors. 'We know this is a very difficult matter for many people in the community,' said National Operations Manager Philippa Hetzel, 'we wish to reassure them that our only concern is the safety of the blood supply.'<sup>1</sup>

## Contamination of the blood supply

The 'difficult matter' of excluding gay men from donating blood goes back to the early days of the AIDS epidemic, when it first became apparent that people with haemophilia, who rely on blood products, were contracting AIDS. The first case of AIDS contracted from a blood transfusion was confirmed in the US in March 1983. Two months later Dr Gordon Archer, head of the Sydney Blood Transfusion Service, issued a public call for 'promiscuous homosexuals' to refrain from donating blood to protect the blood supply from contamination.<sup>2</sup>

Archer's comments angered many gay activists, who felt that gay men were

being equated with promiscuity and disease. Members of the Gay Rights Lobby picketed the ARCBS, which nonetheless proceeded with a request for gay men who had multiple sexual partners to refrain from donating blood. This was followed shortly after by a request for those in other groups deemed at high risk to also refrain; a delay which provided cold comfort to gay activists who felt they were being singled out.

In comments that sound remarkably similar to those made by Michael Cain twenty five years later, Craig Johnston wrote in the gay magazine *Campaign*:

*'When blood collection agencies announce that they don't want any gay donors because of the appearance of AIDS in some gay men, I interpret that announcement as 'all gay blood is bad blood' ... That offends my dignity.'*<sup>3</sup>

Things were to get much worse when fears about possible contamination of the blood supply turned out to be well-founded. In July 1984 a Melbourne man, Bruce Loker, was diagnosed with AIDS after receiving a blood transfusion a year earlier. And in November 1984 when the Queensland health minister announced that three babies had died after receiving blood donated by a gay man, fears about gay men and AIDS went into overdrive.

The subsequent media coverage was devastating for a gay community already beleaguered by rising diagnoses and widespread panic about gay men and AIDS.

For many, the culprit was obvious: gay men. The *Midweek Truth* ran a full page headline quoting the father of one of the babies, who clearly blamed the blood donor, saying: 'Baby victim's father tells AIDS donor: Die, you deviate.'<sup>4</sup>

Such blame was widespread. Professor David Penington, Chair of the National AIDS Task Force, argued that the reason for contamination of the blood supply was that gay men had failed to respond to the request to refrain from donating blood. Gay men were accused

of being selfish, and even of donating blood 'out of spite'.<sup>5</sup>

Governments around Australia responded by introducing declaration forms at blood banks, and criminal penalties for making false declarations. This ignored the evidence which suggested that many gay men had indeed stopped donating blood. Nascent HIV organisations – most of them established by gay men – also emphasised the need to safeguard the blood supply – a position that they still maintain.

It was devastating, too, for people with what we now know as medically acquired HIV. For a time, Australia had the highest proportion of HIV cases acquired through blood transfusion of any western country. Some 30 percent of people with haemophilia who received blood products between 1980 and 1984 acquired HIV – most died.

In a 1985 paper, David Penington wrote that:

*'The male homosexuals protest angrily when this group [those with medically acquired HIV] are referred to as "innocent" or "involuntary" victims of the disease, but certainly their exposure to the risk cannot be minimised by them through modification of their own behaviour as is the case for male homosexuals.'*<sup>6</sup>

What Penington and many others ignored, of course, was that gay men – and others who acquired HIV through sex – were unable to avoid HIV if they weren't aware of it. And in the early 1980s many people were exposed to HIV before the virus was even identified, or before they

realised that they were at risk, or what the risks were.

Much of the fear subsided after 1985 when Australia became one of the first countries in the world to adopt universal screening of blood products. Cases of medically acquired HIV dropped dramatically as a result of this measure. Medically acquired HIV is now rare in Australia, which is thought to have one of the safest blood supply systems in the world. HIV infection through blood transfusion is still possible, though, because even universal screening is unable to detect very recent HIV infections; the so-called 'window period' before HIV becomes detectable. It was this window period that would also be at the heart of Michael Cain's discrimination case.

### **Cain v The Australian Red Cross Society**

Cain lodged a complaint of discrimination with the Anti-Discrimination Tribunal in Tasmania 2004, after he was refused the opportunity to donate blood. In comments that echo those made twenty years earlier, he said, 'I know that I have safe sex,' Cain said. 'It almost felt like I was being accused of being a dirty person'. Cain's case rested on the claim that, as a gay man who practiced safe sex, he was at no higher risk of HIV than anyone else. 'It's really time for the Red Cross to change its policy and focus on whether donors have safe or unsafe sex rather than the gender of the person they have sex with', he said.<sup>7</sup>

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Nascent HIV organisations – most of them established by gay men – also emphasised the need to safeguard the blood supply – a position that they still maintain.

The Tribunal took the case on and despite finding that the ARCBS had acted lawfully, still proceeded to consider the 'substantive issue' of whether the deferral policy is discriminatory, because of the 'fundamental and important nature of this issue'.<sup>8</sup> The Tribunal considered an enormous amount of evidence, with prominent HIV experts appearing for both the complainant and the ARCBS.

A number of arguments were put to the Tribunal; among them that the ARCBS is not a service that would be covered by anti-discrimination legislation, and the legislation did not apply in the case of gifts. The Tribunal ultimately dismissed these arguments, finding that 'it is artificial to consider the Red Cross' services as merely accepting or rejecting offers of donations of blood'.<sup>9</sup> It also found that while Mr Cain's engagement with the ARCBS was voluntary, conditions had nonetheless been imposed on him which were not imposed on all donors.

Instead, the case focused on whether the discrimination was *unreasonable*, and whether it was unreasonable in all circumstances. The ARCBS position was that the 12 month exclusion applying to gay men wishing to donate blood is reasonable, because they present a risk to recipients. 'The major risk of concern to the Red Cross,' the Tribunal said, 'which drives the current deferral policy in relation to the men who have sex with men (MSM) group, is the risk of a donor who is HIV-positive donating blood in the window period when the virus is infectious and transmissible ... but not detectable.'<sup>10</sup>

Mr Cain argued that gay men in monogamous relationships who

practice safe sex should be allowed to donate blood because doing so would not increase the risk of blood transfusion recipients acquiring HIV. Importantly, Cain refused to support any position that would result in an increased risk of HIV transmission; a position which made claims that he was prepared to experiment with the blood supply, or place gay rights over the safety of the blood supply, redundant.

In its decision the Tribunal relied heavily, as would be expected, on epidemiological evidence to assess risk. Professor John Kaldor of the National Centre in HIV Epidemiology and Clinical Research was called by the Tribunal, and gave evidence that 'the risk associated with a monogamous safe sex male homosexual couple is still higher than the risk of infection currently found in the donor pool.'<sup>11</sup> Professor Kaldor's evidence was based on mathematical modelling which took into account the frequency of sexual contact, reliability of condoms, and HIV prevalence in both heterosexual and homosexual communities.

While the evidence and the modelling on which it was based were subject to debate, it appears to have been influential in the Tribunal's decision. Indeed, the development of a model to assess risks to the blood supply was cited by both sides as one of the positives to come out of the case. The Tribunal accepted Cain's argument that some gay men are at higher risk than others but nonetheless, it maintained that 'donor deferral policy must, as a matter of practicality, work on the basis of addressing broad categories of the population and excluding or deferring categories of

donors when, as a group, there is an elevated risk to the blood supply.'<sup>12</sup>

And so the deferral policy stands. For now. The Tribunal emphasised that 'ongoing critical review of the policy will ensure that our blood supply is and will continue as safe as it can be and ensure that if other viable options are indicated then they will be assessed.'<sup>13</sup>

Similarly, Michael Cain, the complainant at the centre of the case, put a positive spin on the outcome: 'I am pleased the tribunal has agreed with my fundamental claim that there are monogamous, safe, gay men who have a lower HIV risk than some of the straight people who can currently give blood', he said. 'This was a knife-edge decision in which the tribunal erred on the side of caution, but given how much of my case it agreed with, I am confident the next time this matter goes to court the outcome will be a new policy.'<sup>14</sup>

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... 'the risk associated with a monogamous safe sex male homosexual couple is still higher than the risk of infection currently found in the donor pool.'



# The verdict in *R v Michael Neal*: mixed messages on responsibility, disclosure and the stigma of HIV

By Michael Williams

The sentence imposed shows that the courts will take account of the effects of incarceration on people living with HIV and ... judges will reduce the overall length to allow for rehabilitation.

Relatively little discussion has followed the verdict and sentencing outcome in *R v Neal*,<sup>1</sup> perhaps the country's most high-profile criminal prosecution of HIV transmission. This silence contrasts with the extensive media reporting of the trial, in which Victorian man Michael Neal was convicted on numerous charges involving reckless and attempted infection of other men with HIV. The sentence imposed shows that the courts will take account of the effects of incarceration on people living with HIV and where, as in Neal's case, individuals are facing a crushing term of imprisonment, judges will reduce the overall length to allow for rehabilitation. Other important issues which emerge from the sentencing remarks include the judge's perspective on personal responsibility and risk-taking; the disclosure of one's HIV status; negative stereotypes about positive people; and access to treatments in prison.

## **Trial, verdict and sentence**

Neal was charged with 30 counts of intentionally and recklessly causing, and attempting to cause, the infection of another person with HIV. He entered a

plea of not guilty on all counts.<sup>2</sup> He was also charged with various other sexual and drug-related offences not relevant

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to the discussion of HIV transmission. In a trial extending to 40 days,<sup>3</sup> the jury heard from several of Neal's victims; psychological experts who testified as to his unbalanced mental state; Department of Human Services officials who issued him with warnings to practice safe sex; and specialist physicians who provided the court with testimony as to the effects of living with HIV. Despite an exhaustive trial, and sensationalist media coverage of the case,<sup>4</sup> the conflicting verdicts suggest that the jury gave careful attention to the factual circumstances of each count. It found Neal not guilty of two counts of intentionally infecting another with HIV and not guilty of nine counts of reckless and attempted transmission.<sup>5</sup> He was found guilty, however, of eight other counts relating to reckless and attempted transmission.<sup>6</sup>

Importantly, Neal was acquitted on the charges laid under s19A of the *Crimes Act* which relate to the intentional infection of another with HIV.<sup>7</sup> The prosecution was clearly anxious to secure the first conviction since the provision was enacted because they apparently rejected a 'plea bargain' offer put forward by Neal's lawyer.<sup>8</sup>

However, because the section requires that there exist both an intention to infect another person with HIV, and an actual infection, it is almost impossible to satisfy the provision on the facts.<sup>9</sup> If the circumstances of Neal's case did not satisfy a jury that the elements of the offence were proved, then it is highly unlikely that s 19A will ever result in a conviction. In addition to the section's practical futility, it also tends to single out and thus stigmatise the condition of HIV, explicitly linking it in the public mind with criminality.

Judge Parsons ordered Neal to serve a maximum term of 19 years in prison with a minimum term of 13 years.<sup>10</sup> In arriving at this sentence, His Honour cited past Australian transmission cases which held that any sentence should aim to deter conduct which places others at risk of infection.<sup>11</sup> The judge also said that the term imposed should deter Neal from endangering any future sexual partners.<sup>12</sup> Thus a long sentence was handed down because it was believed that Neal posed an ongoing threat to other gay men and would not easily alter his behaviour. This was especially the case, given that prior to his arrest, he ignored numerous official

notifications to stop having unsafe sex.<sup>13</sup> The judge also expressed scant hope that Neal could be rehabilitated and noted that he had demonstrated no remorse for his actions, either to the court or by apologising to his victims.<sup>14</sup>

Further, Judge Parsons did not accept that prison would greatly affect Neal's quality of health and thus no reduction was allowed on this basis.<sup>15</sup> His Honour instead relied on expert evidence that current anti-retroviral treatments, if taken consistently, significantly improve life expectancy.<sup>16</sup> The sentence was considerably diminished, however, after the judge applied what is termed the 'totality principle'; a rule which permits a court to impose a lesser sentence where the total imprisonment term would be 'crushing, and as such, would hold out no hope for, and encouragement to, rehabilitation and reform'.<sup>17</sup> Had this 'totality principle' not been invoked, Neal would likely never have been released. The term of imprisonment was further diminished because the judge acknowledged that incarceration would be more burdensome for Neal than other prisoners because he is HIV-positive.<sup>18</sup>

### **Personal responsibility and risky sexual practices**

While the court found that Neal regularly denied being HIV-positive to his sexual partners, or actively deceived them about his status, the judge rejected as a mitigating factor that Neal's victims participated in practices with him which carried a high risk of transmission.<sup>19</sup> The clear implication of Neal's counsel in making this submission was that those who contracted HIV should have been aware of the dangers. The judge wrote that this fact:

Thus a long sentence was handed down because it was believed that Neal posed an ongoing threat to other gay men and would not easily alter his behaviour.

*‘[R]ather than mitigating the offences by you in any way it had the reverse effect, that is, it seems to me that knowing as you did that persons in your particular section of the gay community might indulge in risky sexual behaviour was something you took advantage of, rather than it causing you to be even more cautious with respect to the disclosure of your HIV status.’<sup>20</sup>*

This issue lies at the heart of the debate about whether HIV transmission should be criminalised. Some commentators argue that, where two or more individuals engage in sexual practices that carry a high risk of infection, ‘responsibility’ for the resulting transmission must be shared.<sup>21</sup> This remains a controversial position and seems to find no favour in any of the cases concerning reckless infection so far decided in Australia. In any event, while opinions may differ on whether Neal was entitled to a lesser sentence because his sexual partners should have known of the risks, the case is not ideal for exploring issues of responsibility and risk-taking because it was found that Neal actively deceived others about his status, in effect suggesting that he was HIV-negative.<sup>22</sup>

### **Disclosure of HIV status**

In sentencing Neal, Judge Parson commented on the obligations of positive people to disclose their status to prospective sexual partners. One of the major factors relied upon in deciding on a final term of imprisonment was that Neal posed an ongoing threat to others, and this was because he had not, in the judge’s words, accepted his ‘responsibility as a member of the gay community, with respect to the full, proper

and timely disclosure of your HIV status’.<sup>23</sup> While this may seem an uncontroversial proposition, it has far reaching implications if read to imply that the law requires this level of disclosure. Calling for such disclosure places no responsibility on negative individuals for their own conduct and health.<sup>24</sup> This has caused considerable concern among HIV educators, who have promoted shared responsibility for HIV prevention. The judge did not address whether full disclosure would be required if condoms were worn, or where individuals otherwise sought to reduce the likelihood of infection. The judge’s statement also downplays the difficulties of revealing one’s status, considering the pervasive discrimination within the community regarding HIV. Indeed, in most cases, positive people are reluctant to reveal their status given their fear of rejection, discrimination and even physical violence.<sup>25</sup>

### **Negative stereotypes**

In remarks which largely avoid typecasting positive people, the judge nevertheless invoked a highly negative stereotype in describing Neal’s conduct.

His Honour wrote that ‘[y]ou sought to become your own version of the grim reaper’<sup>26</sup> and ‘continue and pursue your own deviant sexual practices in whatever way you chose inflicting harm’<sup>27</sup>. These may be considered merely gratuitous statements in an otherwise benign judgment but they do suggest that judicial thinking is still shaped by outdated conceptions of both gay sexual practices and of HIV. Such language, particularly emanating from a sentencing judge whose decision will be widely read, reinforces stigma, and should be avoided.

### **Access to care and treatment in prison**

The judge found that Neal’s health would not deteriorate in prison if he continued to take the necessary medication. Paraphrasing the evidence of Neal’s treating physician, His Honour wrote that ‘so long as you receive appropriate medical attention, including access to your anti-viral

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# ‘How do you live like this?’: on stigma and discrimination facing HIV-positive people

By David Menadue

... but the stigma which this person feels about not meeting others’ expectations and being marginalised from the rest of the gay community is directly attributable to living with the virus.

A friend of mine working in the HIV sector told me of a client of his who found the hardest thing about living with HIV was the attitude he got from other gay men when he took them home. ‘How do you live like this?’, was a common response when they were taken back to his basic flat without any of the trappings of a middle-class lifestyle – all he could afford on his disability support pension.

Of course, this is about poverty and class rather than HIV as such but the stigma which this person feels about not meeting others’ expectations and being marginalised from the rest of the gay community is directly attributable to living with the virus. I have been part of conversations where people talked about the so-called easy life disability pensioners have, spending all their time down at the pub or their days blissed out in the backyard doped to the eyeballs. Where middle-class HIV sector managers on reasonable salaries speak about those ‘difficult’ or

‘complex’ people who might be better handled by the Salvation Army or by (virtually non-existent) mental health or drug and alcohol services. Such put-downs by people who are paid to look after vulnerable HIV-positive people have no place in HIV organisations and speak to the need for cultural change amongst some staff at AIDS Councils and other service providers as a part of any stigma and discrimination initiatives in the future.

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A recent report from Sigma Research in the UK entitled *What do you need? 2007–2008: Findings of a national survey of people with diagnosed HIV* reveals that stigma and discrimination still play a significant role in many HIV-positive peoples' lives there, affecting their confidence, self-esteem and their quality of life.<sup>1</sup> Thirty six percent of HIV-positive people (in a sample of 1777) had experienced discrimination in the previous year with 22 percent experiencing it from their own community and 11 percent from their own family. Of those who have experienced stigma and discrimination from their own community, 60 percent said it was due to their HIV status and 22 percent because of their physical appearance. Issues such as poverty, homelessness and mental health problems were a part of this discrimination for some but for others, it was just about demeaning jokes and gossip, or rejection by sexual partners after revealing details of status. Nineteen percent of the Sigma cohort experienced discrimination from health and care professionals including denial of services (a particular problem with dental services), excess precautions, lack of timely access to care (with long referrals to HIV specialists rather than

the provider dealing with simple issues themselves), questions about how people acquired HIV and judgmental behaviour (such as providers moralising about numbers of sexual partners or sexual lifestyles).

The most significant finding for me in this report though was that 71 percent of HIV-positive people in the cohort experienced problems with self-esteem and a lack of confidence that they attributed in some ways to having HIV. Physical appearance (such as having lipodystrophy and significant body image problems), the burden of living with a secret about their status and the health pressures associated with the virus have compounded to seriously affect their quality of life. Anxiety and depression, problems with relationships and their place in society figure as the predominant issues for these people with HIV. These issues are the things they most want changed in their lives, the things they most want HIV service providers to help them with. They are currently the predominant health promotion issues that confront people with HIV in the UK.

How relevant are these issues for people with HIV in Australia?

The *HIV Futures 5* report shows us

that 27.2 percent of their cohort (of 982 people) had experienced less favourable treatment from health providers as result of having HIV (including problems around infection control, breaches of confidentiality and avoidance), although this figure has dropped in recent years (with only 10 percent experiencing it in the previous two years).<sup>2</sup> Almost 16 percent had experienced workplace discrimination and 51.8 percent had had their status disclosed without their permission. The self-esteem issues mentioned in the Sigma Report are not directly reported on in *HIV Futures 5* but the number of those who had experienced a mental health problem was a very significant 51.8 percent (largely depression or anxiety). On relationships, 61.8 percent agreed with the statement 'Few people would want a relationship with someone who has HIV' and 54.7 percent said they were afraid to tell potential sexual partners their HIV status for fear of rejection. There are enough similarities in the findings and in the demographics of our countries that I think we can take the Sigma report as relevant to our situation – and consider much of their findings as transferrable and significant in our understanding of the health promotion needs of HIV-positive people in this country.

There are no quick or easy answers to changing deep-seated prejudices based on class or perceptions about people who have 'made it' in society versus those who are seen by some as 'losers' or living on the margins and best forgotten. Similarly, there are no easy answers to changing some people's perceptions of 'ill' people with HIV. Nor the image of a positive person on the Disability Support Pension (DSP) who is having an easy life, when the

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opposite is what is true: a tough life living on a small amount of money; a path chosen by no one. Nor is it easy to turn around people's irrational fears about being infected by a person with HIV after disclosure – in an environment these days where many people claim not to know of any people with HIV in their friendship networks. When some positive people can live perfectly normal lives without showing signs of their status and are able to keep it from even their closest friends, the invisibility of the virus in some circles is contributing to the stigma people with it experience when the truth is finally revealed.

There are, however, role models who can help to show others the way to move on from these prejudices and to contribute to improving the quality of life of people with HIV. I'm thinking of serodiscordant couples (positive/negative couples) who have overcome their fears about transmission and live perfectly well-adjusted lives. Of HIV-positive people who are able to disclose to anyone they feel they need to, such as sexual partners, health professionals or fellow employees without fear of retribution and a jolt to their self-esteem. Of HIV-negative gay men who have no fears about HIV (and no need to deny its existence either) and believe in their ability to have safe sex and require it of their sex partners. And of HIV-positive people who do the same with people of unknown or a different status.

My concept of a campaign to tackle stigma and discrimination against people with HIV in both the gay community and the mainstream is to hear these people tell their stories through either pithy quotes in advertisements or in more detailed accounts in the press or on the Internet.

It is also about training that is needed for some HIV service providers to shift perceptions of the vulnerable within their areas of responsibility so that there is a real understanding of the social determinants of health for these people and that contributing to improving their self-confidence and self-esteem is the very best they can do to meet health promotion needs for their clients.

Such a campaign also has to speak to HIV-positive people themselves. I know it is not easy for some people to be open about their status, to learn to assimilate it with the ease with which they live with their sexuality or any other point of difference from others. It is however important to feel comfortable in your own skin about things like HIV status whether you can do this through confiding in friends, family or with a counsellor.

It seems important to me that any campaign directed at HIV stigma and discrimination in the future should help positive people to feel confident and comfortable with their status rather than imagining it to be shameful or stigmatising. How can we change community perceptions about people with HIV and the accompanying stigma and discrimination? Initiatives

should include messages to positive people themselves to challenge these behaviours when they occur and to add their personal perspectives. In this way, the world will change accordingly. In many cases though, HIV-positive people will need help to get to that stage where they feel able to do this and I hope HIV service providers see it as their role to contribute to help them reduce the demoralising effects of stigma in their lives.

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# Shame, stigma and secrecy: heterosexuals living with HIV

By Kate Reakes and Pene Manolas

What is worrying is that condom use is not as common in the 'straight' community where people are often more concerned about pregnancy than acquiring HIV.

Imagine you're a heterosexual person in NSW and you've just received the news that you're HIV-positive. You don't know a single other person who has HIV. HIV doesn't affect straight people, does it?

The numbers tell a different story. Between 2003 and 2007, diagnoses of HIV attributed to heterosexual exposure ranged between 18.3 percent (2003) and 25.2 percent (2007) of all notifications in Australia, with an average of 21 percent between 1998 and 2007.<sup>1</sup> Every year in NSW (between 2003 and 2007), there are between 60 and 80 notifications due to heterosexual exposure, amounting to 336 notifications in that period.<sup>2</sup> You'd never know it.

HIV in the broad community is not visible. People of all ages are generally unaware of its prevalence and indeed its risks. What we do know, however, is that regardless of sexuality, most adults enjoy being sexually active; let's face it, few could say they don't enjoy intimacy, sex, and the excitement of 'being involved' with someone. What is worrying is that condom use is not as common in the 'straight' community where people are often more concerned about pregnancy than acquiring HIV.

Young and older people alike are out and about meeting new partners and having intimate relationships before finding ‘the one’ to commit to for a longer period.

This means, as the statistics suggest, that the fairly ‘invisible’ group of people who identify themselves as heterosexual and who are HIV-positive is growing. We need to ask, does the broader community receive the ongoing HIV awareness, health promotion or anti-stigma campaigns that the GLBT community have been exposed to since the beginnings of HIV?

When we talk to the heterosexual community about HIV prevention or awareness campaigns they can only remember the Grim Reaper days; a media campaign that at the time was considered very effective, but also created fear of HIV and of those who have HIV.

In recent times, HIV is again the focus of negative attention, the mass media labelling a Victorian man who knowingly put others at risk of HIV as a modern day Grim Reaper. If the general public, who predominantly identify as heterosexual, are hearing only these negative messages, then the fear and beliefs that HIV is associated only with ‘societal deviance’ increases and victimisation is reinforced.

For a heterosexual person who has just received an HIV-positive test result, beliefs such as those articulated below, are far from helpful – and may instead be frightening, overwhelming and daunting.

*With attitudes and beliefs shaped by negative stereotypes, you don't want to tell anybody because they'll want to know how you got it. There will be questions to answer and assumptions made. Who can you trust with this information? Will people talk about you? If you're in a relationship, how will you tell your partner that ten years ago you had a short-term relationship*

*that resulted in you becoming positive? It might be easier to end it; you might think they'll leave you anyway. If you're single, you might think you'll never have sex or be in a relationship again! Suddenly, sex and relationships might seem all too hard.*

The impact of some of the societal beliefs and attitudes means that many people living heterosexually with HIV live their lives in secrecy, isolation and fear. Some choose not to acknowledge HIV in their lives while others accept their diagnosis but put it out of their mind until the next doctor's appointment, only addressing it when necessary. For most people, however, acquiring HIV, irrespective of who they are or how they get it, is a life-changing event.

Many people living heterosexually with HIV feel it is impossible to disclose their HIV status, due to general ignorance and broad stereotypes.<sup>3</sup> The impact of this stigma and discrimination means that some people will choose not to disclose to close family or friends because of fears of rejection. Phase one of the Straightpoz Study<sup>4</sup> indicates that participants in the study disclosed their status only to a partner, or a few close family members or friends. They describe living with a secret that has a significant impact

on their social and emotional health. Many living heterosexually with HIV described becoming isolated in their attempts to not be ‘caught out’, left in compromising circumstances, or forced to disclose. Many people withdrew from social interactions, becoming socially isolated as a coping mechanism and a consequence of their need for ongoing secrecy. This secrecy and fear of disclosure led to a loss of friendships, potential relationships, a non-existent sex life, a life lacking intimacy; and with some reporting leaving or ending relationships as a result of their diagnosis. To reduce the risk of people finding out about their HIV status, many people often made up and maintained elaborate stories to cover ill health, medical appointments and treatment regimes, in their attempt to pass unnoticed.

The burden of secrecy is also described among partners who are HIV-negative. Many partners report feeling it is not their place to discuss either their, or their partner's circumstances – describing an unspoken or forced silence. Some partners say this can be further alienating as they would appreciate the support of family

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The burden of secrecy is also described among partners who are HIV-negative. Many partners report feeling it is not their place to discuss either their, or their partner's circumstances – describing an unspoken or forced silence.

or friends, but feel bound by their partner's need for privacy. According to phase two of the Straightpoz Study, 'negative partners' rated their own health as poor and attributed this to the stresses associated with HIV.<sup>5</sup>

Frequently at 'Pozhets' (or the Heterosexual HIV/AIDS Service as we're more formally known), we hear reports of stigma and discrimination from clients and other HIV sector workers. This was reflected in the Straightpoz Study<sup>6</sup>, where people living heterosexually with HIV reported experiencing stigma and discrimination from family members, friends, work colleagues, government services, their employers and others; and having their confidentiality breached in various settings, by a variety of people. Indirect discrimination was also experienced through friends or colleagues, who, when discussing HIV or people living with HIV in a negative manner, were often unaware of their friend's HIV status.

The greatest discrimination, they felt, came from healthcare professionals. Reports of being treated differently, by a health worker who is overly

inquisitive as to how a straight person became positive, with alarmist, judgmental and uninformed reactions are not uncommon.<sup>7</sup> Non-HIV healthcare workers have suggested that straight people with HIV don't deserve medical care or that they are 'deviant'. These responses create distrust of health care professionals (or other people in general) in the future. They create alienation, extend secrecy to the health care setting, and limit access to care required from health and support services.

The sense of shame and secrecy described above, places greater emphasis on the relationships people living heterosexually with HIV have with their HIV doctor or specialist. Many participants of the Straightpoz Study believed that they didn't need to be well informed about HIV information, new developments and treatments, as their HIV doctor would be up-to-date. The relationship with the HIV doctor was therefore of vast importance: for some, seeing the doctor was the only time HIV was discussed and addressed in their lives, and the HIV doctor was liked and trusted

(in contrast to responses about other non-HIV health care professionals). With HIV doctors and specialists, people living heterosexually with HIV reported feeling respected, welcome and accepted, safe and comfortable; enjoying open communication with a person with whom they shared a common humanity.<sup>8</sup>

HIV-negative partners reported mostly being treated well by HIV doctors and specialists. However they felt inadequately supported as carers, with a lack of validation as the 'negative partner'. 'HIV-negative partners' reported experiencing similar responses from non-HIV healthcare services, being told to never have sex again with their partner and being urged to end their relationship. Some were told they were foolish and irresponsible for being in such a relationship, that they were wasting their lives, with implications that they were morally corrupt.<sup>9</sup>

While clients of the 'Pozhet' service continue to report ongoing experiences of stigma and discrimination as a result of HIV, they also report that the situation has improved and are often optimistic. Ideally, awareness of HIV among the general public will increase, the myths and stereotypes associated with HIV will be dispelled, and there will be greater awareness that anyone can be affected by HIV and be living with HIV.

At 'Pozhets' we work towards further reducing HIV-related stigma and discrimination, and its subsequent impact in the health care setting. To enable a more informed health service and supportive environments, Pozhets – the Heterosexual HIV/AIDS Service – are developing training packages

Reports of being treated differently, by a health worker who is overly inquisitive as to how a straight person became positive, with alarmist, judgmental and uninformed reactions is not uncommon.

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# Women and HIV: the impacts of stigma and discrimination

By Rachel Lennon and Dawn Wilcock

Contrary to stigma commonly associated with HIV and women, the majority of infections are attributed to sexual encounters with male partners and not through sharing needles or sex work.

By the end of 2007, 2,025 women living in Australia had been diagnosed HIV-positive. Of this figure, 527 women had died.<sup>1</sup> Contrary to misconceptions commonly associated with HIV and women, the majority of infections are attributed to sexual encounters with male partners and not through sharing needles or sex work. This article looks at some of the issues faced by HIV-positive women in experiencing stigma and discrimination.

## Heterosexual transmissions

Concurrent with existing data in Australia, the United Nations and World Health Organization (WHO), report a global trend for sustained increase in the transmission of HIV through heterosexual contact.<sup>2</sup> Potentially, these trends are a predictor for rises in infections amongst Australian women, requiring a deeper knowledge of the social differences between positive women and positive men. The issues faced by HIV-positive women include considerations of childrearing, menopause and other complex physical changes they face throughout their lifetimes. This does not take into account the psychological issues faced in disclosing their status to their families, and/or telling their children that they too are HIV-positive through parent to child transmission.<sup>3</sup> Additionally, there is a lack of research about the effects of ageing, physical changes and

reactions with HIV medication.<sup>4,5</sup> However compelling these issues may appear, HIV-positive women remain a minority within a minority.

## Trends in Australia

Heterosexual transmission in Australia is on the rise. According to the National Centre in HIV Epidemiology and Clinical Research (NCHECR) *Surveillance Report* (2007), there has been an increase of 35 percent in HIV heterosexual infections between 2005 and 2006 across all Australian states. Western Australia data shows that in 2005, heterosexual transmissions represented 50 percent of all new infections in the state. This compares to 39 percent for the average of the previous five years. In Victoria, surveillance data has shown that heterosexual notifications have doubled in the past 24 months.<sup>6</sup>

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*'Women living with HIV/AIDS struggle to be seen and heard within the current HIV community. This struggle feeds their existing sense of isolation. In addition to their struggle to be acknowledged and be embraced within the HIV community, they fear disclosure, particularly to the wider community.'* (Jayne Russell, Researcher, ARCSHS)

HIV amongst women is perceived as an infection that is contracted through 'bad behaviour' such as sex work or injecting drug use. Research shows that rigorous screening for STIs and extensive education about the impacts of unprotected sex has in fact resulted in low incidence of STIs amongst licensed brothel workers.<sup>7</sup> Needle exchange programs and education around injecting drug use have also resulted in low incidence of HIV in the injecting drug community. For Victorian women living with HIV, heterosexual relations with long-term male partners have been the predominant mode of transmission.<sup>8</sup>

### Impacts of stigma and discrimination

*'I take seven pills daily that make me sick to my stomach. I experience nausea, diarrhoea, vomiting and the worst of all, mood swings. But yet it is still not the worst part of having HIV. It is the stigma.'* (A Positive Woman)<sup>11</sup>

HIV-positive women in Australia experience greater levels of stigma and discrimination, have less support to draw upon<sup>12</sup> and, until diagnosis, many positive women never thought they were at risk of HIV infection. The shock of diagnosis can result in delaying commencement of treatment which may affect a positive woman's health if it is needed right away. A positive diagnosis may have difficult implications for the relationship with the person who infected them, particularly if children are involved. This may lead to negotiations around the future of the relationship at the same time as understanding the ramifications of being HIV-positive: an incredibly difficult time.

### Positive Women

**Positive Women (Victoria) seeks to provide support and advocacy for these women, and to raise the profile of HIV and women in the community.**

In the early years of the HIV epidemic, public conceptions of women with HIV focused on childbearing and saw women as the main carriers of HIV who passed the fatal infection on to her family.<sup>9</sup> Even though HIV has a higher profile in the community, there is still a lack of research and action addressing the physiological, sociological and emotional impacts of HIV on women.<sup>10</sup> There is also a notable gap around advocacy for positive women. Taking into account the diversity amongst women with HIV, the impact of HIV on women needs further exploration alongside social determinants, effective prevention strategies and more robust support models.

Positive Women (Victoria) aims to build an evidence base substantial enough to bring about sustainable lasting change either on a policy level or in the consciousness of the public.

In Australia, sexual health is largely seen as the responsibility of the woman while a man's sexual practices (safe or unsafe) are expected to be accepted by the woman.<sup>13</sup> Additionally, it is suggested that heterosexual men tend to discourage condom use in sexual relationships and have more sexual partners.<sup>14</sup> The incidence of violence against women is higher when they ask their partner to use a condom or when their partners discover they have attended HIV testing and counselling.<sup>15,16</sup> This type of behaviour is unacceptable, as men need to be equally responsible for safe-sex practices.<sup>17</sup>

Stigma and discrimination have both physical and psychological impacts on people living with HIV/AIDS.<sup>18</sup> Negative social responses have been shown to affect the levels of uptake in antiretroviral medication and some services for people living with HIV. Out of fear of stigma and discrimination, some positive people are less likely to: participate in HIV services such as education programs around preventing mother-to-child transmission in pregnancy; receive treatment information/counselling; or participate in other programs aimed at building better levels of social inclusion.<sup>19,20</sup>

The impact of discrimination on HIV-positive women's mental health includes high rates of depression and trauma resulting in disease progression by decreasing CD4 lymphocytes and increasing viral load.<sup>21</sup> Unfortunately, depression is one of the most common mental illnesses amongst people living

with HIV with higher rates occurring among women.<sup>22</sup> One study examining the effects of depressive symptoms and mental health on highly active antiretroviral therapy (HAART) uptake amongst HIV-positive women found that poor mental health and depressive symptoms significantly reduced the probability of using HAART.<sup>23,24</sup> Thus, strong support networks are crucial and the level of support a woman can expect from her family and friends is indicative of when and how she discloses to them. Parents usually respond with shock and can communicate this in a number of different ways, both supportive and destructive. It has also been revealed that women will 'put off' treatment as they find it distressing to their mental health.<sup>25</sup>

### Positive parenting

In Australia in 2002, 50.2 percent of women infected with HIV/AIDS had dependent children<sup>26</sup>, and the number of HIV-positive women having children has increased since then. Research has shown that stigma towards positive women is a minor factor in non-disclosure to children; a larger one is the fear that their children will experience stigma.<sup>27</sup> Parents of children's friends are not always aware of the low level of transmission risk involved in HIV and can put barriers in the way for their children in socialising with children of HIV-positive mothers.

Challenges faced by positive women when disclosing their status to children include fear of rejection, inability to control secondhand

disclosure by their children, an increase in vulnerability for the child and the child's ability to cope with such information.<sup>28</sup> Meanwhile, the majority of women living with HIV are infected by male partners who may have acquired HIV from having sex with another person (male or female), or intravenous drug users. Therefore, providing explanations that are appropriate for children can be very difficult.<sup>29</sup> Women who become pregnant while positive seem to be able to disclose more freely than women who already have children when diagnosed.

### Addressing the issues

In Australia, a great deal of communication about HIV has been predominantly in the gay community. Most gay clubs and bars have accessible information about HIV; gay dating websites have information about keeping safe from HIV. Women are disadvantaged by a lack of timely and accessible information about HIV. Since the campaigns of the late 1980s featuring the Grim Reaper, no other major campaigns about HIV/AIDS have been focused on women. The campaigns available to the public had adopted shock tactics in relation to HIV/AIDS rather than the use of educational means to facilitate public behavioral changes in sexual practice. Regardless of the blame women receive for transmitting the virus, there have been no gender specific campaigns.<sup>30</sup>

It is clear that stigma and discrimination are major hindrances to accessing medication for HIV-positive women. Stigma also negatively impacts upon mental health, increases violence and ultimately, has led to further transmission of HIV and disease progression. With infections in women on the rise, it is time to develop methodology to address diversity and poverty, and turn it into a substantial campaign. We have seen several women-specific programs and strategies assist in preventing HIV transmission and HIV disease progression such as peer support programs, counseling, and education programs to name a few. Many of

these have been implemented by organisations such as Positive Women Victoria. But we need to see more.

For further information about HIV and women, the table below provides service contacts.

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### Organisations to contact

#### Positive Women Victoria

[www.positivewomen.org.au](http://www.positivewomen.org.au)

T: 03 9076 6918

#### Straight Arrows

[www.straightarrows.org.au](http://www.straightarrows.org.au)

T: 03 9076 3792

#### PEP (Post-Exposure Prophylaxis)

T: 1800 889 887 (24 hours)

#### Positive Counselling

[www.positivecounselling.org.au](http://www.positivecounselling.org.au)

T: 03 9530 2311

#### PLWHA Victoria (People Living With HIV/AIDS)

[www.plwhavictoria.org.au](http://www.plwhavictoria.org.au)

T: 03 9865 6772



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# Solutions to stigma

By Daniel Reeders

Often, the concept of stigma stands in for the social 'remainder' – the stubborn, irrational prejudice we believe our carefully formulated strategies cannot hope to change.

'Stigma' is frequently invoked as HIV sector shorthand, gesturing at a wide range of prejudicial attitudes, discriminatory practices and unpleasant experiences. We don't always know how to define it, but we know it when we see it. Often, the concept of stigma stands in for the social 'remainder' – the stubborn, irrational prejudice we believe our carefully formulated strategies cannot hope to change. In successive state and national HIV/AIDS strategies, the crucial importance of stigma is repeatedly acknowledged, but almost never included in priorities for action. The enormous breadth of the conceptual field seems to have brought educational policy and strategy to an impasse.

In 2008 the NAPWA Health Promotion Education Network commissioned the development of a discussion paper and skills workshop in time for the AFAO Educators Conference in Wollongong, seeking to build consensus around a specific definition and shared language for addressing HIV-related stigma. A review of the literature found our sector is not alone in struggling with the breadth of the concept, and some great work has recently been done to identify specific and practical dimensions of the problem. This article offers a pragmatic conceptualisation of stigma, considers its individual and cultural manifestation, and finally suggests some possibilities for a programmatic solution.

## Conceptualisation

In *Stigma: Notes on the Management of Spoiled Identity*, Erving Goffman first defined stigma as 'an attribute that is deeply discrediting within a particular social interaction'.<sup>1</sup> The name itself refers to a mark, focusing attention on its bearer, instead of the social process investing it with power and meaning. Bruce Link and Jo Phelan suggest this approach sometimes looks like blaming the victim, pointing out a comparative lack of research into the psychology of people who discriminate.<sup>2</sup> Similarly, queer theorist Michael Warner has argued that silence is a privilege of normality, sustained by requiring

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deviance to announce and constantly narrate its presence and difference from the norm.<sup>3</sup>

This is an important perspective: some of the strategies we adopt to challenge stigma and social hierarchy – such as coming out, disclosing positive serostatus, Pride March and Mardi Gras, and visibility campaigns – might appease and unintentionally reinforce the underlying social process. Recognising this problem, Guy Parker and Peter Aggleton called for a stronger focus on stigma as a social process which sustains and reproduces relations of power and control that lead to social marginalisation.<sup>4</sup>

Reviewing the incredible profusion of subtly-different invocations of Goffman's original work, Link and Phelan propose a definition of stigma based on the co-occurrence of five components: (1) labelling, (2) stereotyping, (3) separation, (4) status loss and discrimination, (5) social power. Although their understanding of power is rather clunky, it usefully operationalises stigma as a set of interrelated social processes, each of which may be susceptible to disruption by well-funded community health interventions. The component

definition shows how much is packed into the concept of stigma, and it's worth taking some time here to explain and illustrate the key terms.

**Labelling.** In the early days of HIV, Kaposi's Sarcoma ('KS', or 'wasting') did the job; then it was physical side effects of medication. As the drugs have improved, positive status has for many become concealable, and this shift has produced great anxiety about whether people living with HIV will 'do the right thing' before and during sex.

For some positive people, this has intensified 'felt' stigma and fear of disclosure. Others have chosen public disclosure, often via Internet profiles, which might accede to the demand to identify your differences but also seems associated with enhanced resilience and a sense of relief – showing the tension involved in maintaining what our profession calls 'confidentiality' but which stigma constructs as 'secrecy'. These examples illustrate how stigma can operate even when labelling is merely potential or possible.

**Stereotyping.** Stereotypes are not just 'incorrect images' or myths needing to be 'dispelled'; they serve a social purpose and encode a dense network of associated meanings into

a figure of knowledge. Showing pictures of positive people *sans* horns and a tail is not enough to dissolve these associations.

**Separation.** This refers to the *us-vs-them* thinking that stigma produces, and this fact has enormous relevance for prevention, since it facilitates othering – the process of discounting one's own responsibilities and outsourcing them as obligations upon the Other.

**Status Loss and Discrimination.**

At this point stigma begins to have individually perceptible effects, as people living with HIV feel devalued as people by their positive status, and every occasion of disclosure re-enacts the moment of diagnosis. With sensational media coverage of criminal prosecutions, every person with HIV now bears the loss of status associated with potential criminality – and the anxious interrogation of their sexual practice for signs of illegal onward transmission. Stigma is most obviously manifested in discrimination – but by this point, it has usually gathered around itself underlying justifications and a cover story, such as 'we can provide better, more specific care if we know their status' (at a medical imaging facility).

**Social power.** Link and Phelan insist that only socially powerful groups can stigmatise others. However, Harriet Deacon, writing from South Africa, notes that people at *any* level of society can participate in and perpetuate the social processes constituting HIV stigma.<sup>5</sup> Parker and Aggleton adopt Foucault's definition of social power as something more fluid – more like energy than a stable attribute or possession – to argue that stigma is centrally concerned with domination and marginalisation and how these are deployed to maintain the social order.

With sensational media coverage of criminal prosecutions, every person with HIV now bears the loss of status associated with potential criminality – and the anxious interrogation of their sexual practice for signs of illegal onward transmission.

The take-home point is that discrimination occurring without Link and Phelan's other four components is not stigma. Sexual rejection practiced because a positive guy only wants seroconcordant unprotected sex does not stigmatise negative men. Likewise, if an HIV-negative guy is honest about his fear of HIV, admitting it's how *he* feels rather than projecting it onto positive men in general, then he's able to respond to serostatus disclosure without (inevitably) making a positive guy feel dirty and rejected.

### Manifestation

The component definition offers readers a handle on the 'what' of stigma. Looking at how it plays out – its individual, cultural, and governmental manifestations – offers a grip on the 'why'.

#### Individual

One of the striking things about prejudice is the lengths to which individuals will go to defend and rationalise objectively discriminatory beliefs when these are challenged. Techniques like motivated reasoning, denial, defensive avoidance, reactance, and message discounting are employed as *fear control* to manage strong emotional states like the fear/anxiety provoked by thinking about HIV infection.<sup>6</sup>

In an essay on 'The Psychology of Security', about the politics of fear around national security, Bruce Schneier makes the important point that fear (the ancient, inbuilt fight-or-flight response) can *neurologically override* the rational processing functions of the brain. 'We have two systems for reacting to risk – a primitive intuitive system and a more advanced analytic system – and they're operating in parallel.'<sup>7</sup>

The neocortex (rational brain) knows that condoms afford protection against HIV, but the thought of HIV provokes strong emotion, and stigma/discrimination can be understood as a socially-intermediated version of the fight (hate speech) or flight (sexual rejection) response. In the brain, the neocortex is described as the *slow-learning* system, and time and conscious effort are needed to train the brain to overcome the initial and immediate intuitive assessment of risk embedded in the presence of strong emotion.

The time and effort needed are visible in the slow, deliberate learning process some HIV-negative gay men undertake to overcome their practice of stigma against HIV-positive men as potential sexual and relationship partners. It certainly makes it clear that individuals cannot simply make a snap decision not to stigmatise people living with HIV, and that trying to challenge these attitudes will be counterproductive if it simply provokes *more* fear/anxiety and defensiveness.

It also shows the alignment of stigma reduction with HIV prevention objectives, since the same psychological processes that buttress stigma and discrimination also impede the

acquisition of knowledge and skills around condom use and sexual negotiation. As Catherine Dodds found in a study of responses to a question about criminalisation included in the 2006 Gay Men's Sex Survey in the UK, respondents who supported punitive legislation and emphasised the exclusive responsibility of people living with HIV to prevent transmission were more likely never to have tested for HIV and to show higher need for HIV prevention education.<sup>8</sup>

#### Cultural

The cultural manifestation of stigma has been very much on display in recent years with moral panic in the media around the public health management of HIV-positive 'sexual predators'. In a chapter for a forthcoming NAPWA monograph on criminalisation, I have described moral panic as the acute phase, and stigma as the chronic phase of the same social process – of devaluation and marginalisation of people according to selected aspects of difference.

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# The dynamics of shame: implications for counsellors working in alcohol and other drug settings

By Rebecca Gray

Shame, then, is described as that which mortifies and silences. It distorts perception and creates a sense of self that is unlovable, dirty and low.

## What is shame?

*Shame lies hidden behind inaccurate words, symbols that fail to grasp the inner experience of the self. Even the word, shame, is a rather poor one, though I know of none better, for it fails to convey either the feeling of exposure inherent to the experience or the sense of despair and anguish that can accompany extreme moments of utter worthlessness.<sup>1</sup>*

Kaufman here describes the overwhelming and deeply unpleasant experience of shame that many of us have experienced at some time. And while shame in moderate levels has been described as a healthy sign of a balanced ego that sits between arrogant contempt and abject humiliation<sup>2</sup>, this kind of chronic shame is rarely experienced.

For me, it is public speaking gone badly, for others it might be the exposure of some salubrious behaviour<sup>3</sup> or when describing an experience of trauma<sup>4</sup>. For many clients of

counsellors and psychotherapists, it occurs in that moment of acknowledgement of a deeply personal trigger or painful memory. And this is where it becomes difficult; shame silences and paralyses and this can be a considerable impasse in recovery that is based upon dialogue<sup>5</sup>.

Shame, then, is described as that which mortifies and silences. It distorts perception and creates a sense of self that is unlovable, dirty and low.<sup>6</sup> In addition to this, other factors, like shaming treatment models and social perceptions of clients, can compound barriers, especially where treatment is undertaken in a field marked by stigma, in this case the alcohol and other drug (AOD) services and their clients who are at risk of HIV/AIDS and other bloodborne viruses.

The prevalence of HIV among AOD service clients in Australia is low.<sup>7</sup> This is attributed to the wide availability of injecting equipment from Needle

and Syringe Programs.<sup>8</sup> However, it is widely acknowledged that HIV transmission may increase when combined with other factors, such as, sexual practice or recent initiation into injecting drug use.<sup>9</sup> Another risk, for potential clients of AOD services, is the hindrance of being stigmatised, by their perceived 'chaotic' lifestyle or by the social perception that they present a greater threat to the community by transmitting bloodborne viruses, such as, HIV or HCV.<sup>10</sup> Ultimately, this further alienates users of AOD services from equitable health care services and local research demonstrates the need to train staff around their implicit negative attitudes.<sup>11</sup> When combined with increased shame, this can lead to a combination of insurmountable barriers to treatment seeking and treatment outcomes. What, then, are the implications for counselling practice?

### Shame and alcohol and other drug counselling

When working in AOD settings, counsellors often encounter shame in their clients.<sup>12</sup> This shame relates to the stigma and sense of failure when acknowledging 'addiction', where the identity of the client becomes imbued with a sense of defect or monstrosity, as well as shame inspired by long term intra-psycho processes that emerge from personal and social adversity in relation to significant relationships and cultural phenomena. At times, the counsellor may themselves experience shame, as they perceive their own professional performance to be flawed. In short, the therapeutic process is wrought with ever-compounding dilemmas that relate to treatment models and worker client relationships in AOD settings. Outlined here are some of the themes that emerged from interviews with counsellors who work with AOD clients. (Counsellors are anonymous to protect professional boundaries).

One of the key features is the prevalence of counsellors' perception of shame and stigma as central to their work with AOD clients. They saw shame as an inevitable element of counselling clients entering residential rehab and made statements like: '[shame] goes hand in hand with drinking and drugging' and 'I've never met anyone not dealing with shame issues'. Interestingly, there was a perception that all clients need to deal with shame issues. When presented with questions around shamelessness, the majority of counsellors responded by stating that this was a polarisation or avoidance of shame issues. They were also keen to add that while clients may 'appear shameless ... that's actually a cover-up of shame and guilt'.

The expectation of 'shame-work' was viewed as a necessity for clients of AOD services. However, counsellors were also keen to acknowledge that this be approached tentatively. They acknowledged that to name the client's experience, as 'shame', could be shaming in itself<sup>13</sup>, and would go beyond the boundaries of client-centred practice.

Counsellors also viewed shame as a trigger to problematic drug use which matches literature on shame that asserts a direct link between the anxiety provoking nature of shame and the need for alcohol and drugs.<sup>14</sup> The majority reflected on the need to work on shame in order to reduce the possibility of relapse and enhance the opportunity for recovery. One counsellor described her work in the following way:

*It's just the shame and guilt and getting into all that stuff... And just, you start looking at why did they ... use drugs and alcohol? Like that level of self esteem has to be quite low for them to abuse it for that length of time, to not think they deserve anything better.*

Another counsellor described the cyclical nature of the shame experience,

in that behaviours exhibited while intoxicated can add to the shame burden of the clients:

*They wouldn't be here if they didn't have shame or guilt about what they were doing. They wouldn't be here.*

Shame, then, is a dynamic that moves between individuals, around a group or community and simultaneously within the self, as the person's relationship with the self responds to social and relational cues and implicit morals or judgements. The action of entering a rehab is one that can shame the individual as they acknowledge their failures to manage their drug use, reflect upon their mistakes, and are all the while labelled by their community as an 'alcoholic' or an 'addict'. One counsellor talked about this in the following way:

*Shame ... I think people can feel it ... looking at that person and saying "you're just a junkie" ... I hear it in counselling sessions [with clients] ... and [they feel] they're not respected as human beings.*

### The impact of stigma

The majority of the interviewees reflected on the impact that stigma has on their work with AOD clients. One counsellor stated:

*And generally most of the [clients] by the time they reach here have been shamed and 'guilted' by everyone, by themselves and everyone else. And their self esteem is just not there. Their self-worth just isn't there.*

When asked how they managed this dynamic in their work with AOD clients, the counsellors stated overwhelmingly that there was a need to be 'gentle' and be careful not to inadvertently shame clients further.

*continues overleaf*

One counsellor stated:

*I think you have a real potential to kind of replicate the shame that people have experienced externally and internally from being labelled. Because most people are generally labelled as 'alcoholic' or 'addict' or ... yeah, yeah, by their behaviour ... behaviour is not the person.*

The majority of counsellors interviewed, stated that this labelling and diagnosing directed at their clients was the greatest source of workplace tension. This was described as causing vicarious trauma for workers who may observe another worker, accidentally or deliberately, shaming a client, as well as their own shame when remembering mistakes they made early in their careers.<sup>15</sup>

Ultimately, counsellors repeatedly described shame as integral to counselling. It can be a trigger for problematic drug use and the stigma of using intensifies this shame in a way that inhibits recovery. Moreover, counsellors described the mortifying nature of shame as a significant treatment barrier and felt that, through inexperience or coercive treatment settings, they may inadvertently shame their clients. The overall tone of these interviews revealed a tension between re-humanising the clients while observing practices that might hinder or even counteract this work. This was felt to be detrimental to the clients' recovery and to have a negative

impact on the workers. Furthermore, participants stated an ongoing tension between the relationship they had built with these clients that was based upon an unconditional positive regard (a prerequisite of counselling practice) and the social view of these clients as 'junkies' or 'criminals'. When asked what might happen in a therapeutic setting if the workers did not show positive regard, one counsellor stated:

*I think people would leave before the end of the program. They don't come in to a setting like this to be judged ... they're basically throwing their hands up and saying "help me!" ... You would never get a rapport.*

Stigma was discussed across the interviews as a barrier to the process and was thought to impact on the attrition rate. The use of unconditional positive regard and the importance of client engagement is not a new concept to counselling. However, the expectation to maintain a therapeutic relationship in a context that might view the client negatively was stated as a considerable barrier to counselling AOD clients and has a direct effect on the success of treatment.

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Moreover, counsellors described the mortifying nature of shame as a significant treatment barrier and felt that, through inexperience or coercive treatment settings, they may inadvertently shame their clients.

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colour of his skin, or his religion, or discriminates against a lesbian based on her gender? How can a group that is subject to fear and ignorance experience fear and ignorance of transgender people? This is a question that the Queensland Association for Healthy Communities was seeking to understand when it rolled out its 2007 Pride Festival community campaign and its discrimination in the LGBT community survey.

The causes of prejudice are still debated, but the field of psychology argues that we frequently make false generalisations; not through malice but because it is often easier to do this than try to understand the real complexities of the world. Extending this thinking further, it is suggested that prejudice is a negative consequence of our natural tendency to categorise the world. These prejudicial stereotypes are not based on fact, but rather on what we think is right from our upbringing and limited experiences with these groups. But ultimately, whether we are talking about psychological pressures faced by LGBT people living in a discriminatory and homophobic society, or the effects of discrimination specifically from within the LGBT community towards other

LGBT people, the effects are the same. In surveying the community, people identified experiencing negative outcomes such as suicidal thoughts and depression, low self-esteem and anxiety as a result of discrimination from other LGBT people. Along with self-harm, suicide attempts and drug and alcohol dependence are all effects which have been linked with the experience of prejudice and discrimination.

As far as the LGBT community is concerned, this problem can be made more difficult by the issue of less visible expressions of discrimination. Given the general lack of LGBT relevant imagery and venues or social opportunities in the wider community, this is a particularly relevant aspect of the problem. The concern is that there are less overt forms of discrimination occurring, such as a lack of visible imagery for some groups in the gay and lesbian press and in the community. This can result in individuals and groups feeling invisible and disconnected from the larger LGBT community, resulting in the general disempowerment of people. This type of less overt discrimination can also take the form of inadvertently excluding groups, or inadvertently

preventing their access. This can involve things like groups, events and venues not being as inclusive for all groups as they could be, through to actually not being physically accessible for people with disabilities. Simply being silent in terms of discrimination, even just about the simple fact that it exists in the LGBT community, can also be hugely disempowering for those who experience it.

Using surveys, a study into this issue highlighted a number of key facts about the experiences and perceptions of the LGBT community regarding this type of prejudice. Firstly, and most surprisingly, 60 percent of people identified that they had directly experienced this type of prejudice, and that most of it had occurred at an LGBT nightclub. Importantly, it is not just people experiencing this discrimination first hand who had a view on the issue. Ninety percent of survey respondents felt that this prejudice was occurring, meaning even those who hadn't experienced this sort of treatment themselves had witnessed it, or otherwise knew it occurred. This indicates a real awareness of the issue in the community.

People also had thoughts about who were the targets of this treatment. The groups that respondents saw most prejudice directed at were the aged community first, closely followed by the transgender community; the lesbian community was the third most discriminated against. Closely following these groups for experiences of discrimination were LGBT people of an Asian background, HIV-positive people, and those with a disability. Further adding to our body of knowledge, the most common type of prejudice that people were experiencing was public ridicule; exclusion and

Firstly, and most surprisingly, 60 percent of people identified that they had directly experienced this type of prejudice, and that most of it had occurred at an LGBT nightclub.

verbal abuse were each additionally experienced by half of all those who had been discriminated against.

So we were able to quickly build a picture of people's experiences. A lot of people were being discriminated against, and this was occurring in the spaces that they were supposed to be able to go to for refuge, support and belonging. But this was only half the picture. We also needed to know how people were dealing with these experiences and how to prevent them from continuing.

Unfortunately, the majority of people just ignored it, with some people speaking to their friends about it. Almost half of all people said that they did get some limited support from those around them when it occurred. Very few people thought about using a professional support service to help them deal with this: our results show that most people didn't think the experiences had enough of an impact to need that kind of support. However, almost half said that they didn't know any of these kinds of services existed or that they didn't think any services could help them with this unique problem.

When we asked about the best ways to resolve the problem, the majority of people identified that they thought raising the visibility and knowledge of groups would reduce this prejudice. Given this, it is worth noting that the LGBT groups that were seen as not being understood were the transgender community (the least understood), the Asian community (second least understood) and the lesbian community (the third least understood). Unfortunately, the key outcome of these experiences of discrimination for individuals was for people to withdraw from the scene and stop going out. And of course, this is really concerning

because we know that the scene and having supportive friends are important for a variety of reasons. These things all play a role in preventing a variety of mental health and even physical issues.

At the end of the day it is clear. The community has told us that they want to talk about these experiences with their family and friends. As a community, we can be supportive of anybody who has experienced this type of prejudice.

We also need to make it clear that this type of discrimination is not accepted in our community. And that we recognise that, as a minority community, we will not perpetuate discrimination and prejudice based on race and culture, age, gender, disability or HIV/AIDS. That as a community of people who face prejudice based on our own sexuality, we will not inflict even more prejudice on our own community. And as a community, we can take every opportunity we are presented with to make our community inclusive of these groups. We can make these groups a visibly included part of our community. This means making them visible in our media, in our venues, and in our events and the places we socialise.

By talking about it and acknowledging the problem, we can help validate the experiences and feelings of people who have been discriminated against. This in turn can empower and allow people to talk about their experiences and begin to heal and resolve the issues in his or her life. We have a long way to go: we don't fully understand all the issues people face when dealing with this problem. But this work and the great work in the area of racism and prejudice that other organisations like ACON are doing will help increase our understanding. Hopefully one day, all LGBT people will have the awareness and knowledge needed to be able to truly put themselves in the place of others and understand the power of their words and actions.

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We have a long way to go: we don't fully understand all the issues people face when dealing with this problem.

# Would You Wear It? The development of ACON's inclusion campaign

By Solomon Wong and Michelle Sparks

The 2005 Cronulla riots, where hundreds of Anglo Australians rampaged through the streets of beach-suburb Cronulla, displaying Australian flags and attacking Middle Eastern people on sight, have left a scar on the consciousness of all Australians. Racial discrimination within the GLBT community, however, has been less overt.

Stigma and discrimination of any kind weaken our community, and that includes racial discrimination within the gay, lesbian, bisexual and transgender (GLBT) community. Discrimination within the GLBT community is often overlooked, guided by the incorrect assumption that as collective victims of homophobic discrimination, we are aware of the impact of discrimination and would not wish it upon others, least of all those within our own community.

While Australia has legislated against racial discrimination, there are clear markers of racism in mainstream society. The xenophobic policies and public statements of Queensland politician, Pauline Hanson during the 1990s rallied substantial public support which subsequently channelled into the federal government's policies under John Howard. The 2005 Cronulla riots, where hundreds of Anglo Australians rampaged through the streets of beach-suburb Cronulla, displaying Australian flags and attacking Middle Eastern people on sight, have left a scar on the consciousness of all Australians. Racial discrimination within the GLBT community, however, has been less overt.

Racism in the GLBT community most commonly takes the form of social exclusion, offensive jokes and verbal abuse, according to data gathered by ACON, the leading agency promoting the health and wellbeing of the GLBT community in NSW. The history of struggle against racism in the GLBT community has been sporadic. While the issue has been long noted, there has not been enough momentum for a concerted effort. It was unaddressed, but not unnoticed. A racist incident in 2004 sparked a community response.

## Impetus for the Campaign

ACON's response was initially sparked by comments in a 2004 drag performance at a prominent Sydney nightclub which were perceived by community members as racist. With the support of ACON, the Queer

Racial Harmony Collective (QRHC) was formed. QRHC subsequently held a forum for community members to get together to discuss the nature of racism in the GLBT community and possible ways to address it. Anecdotal evidence of racism within the GLBT community over several years was noted and community members recalled previous community attempts to address it but no documentation could be located.

As a health promotion agency, ACON is aware of the impact that discrimination can have on mental and physical health. On the individual level it affects self-esteem, feelings of community belonging and the ability to develop social and support networks. At an institutional level, it can discourage or limit access to relevant health services, or decrease the quality of service provision. This is particularly pertinent given that culturally and linguistically diverse (CALD) populations are prioritised in the *NSW Health HIV/AIDS Strategy 2006–2009*.

ACON used the information from the QRHC forum to develop the *Would You Wear It* campaign.

## Would You Wear It?

The campaign challenges the broad GLBT community to not be complacent about racism. It was noted that there are few people who are committed racists for ideological reasons but that the majority of people subscribe to a 'fair go for all' philosophy. Racism most often occurs when people fail to stand up for inclusion

by, for example, laughing along to a racist joke or failing to say something to challenge a racist remark by a friend. Most people would not want to wear the label 'racist' that their silent consent implies. The question 'would you wear it?' was therefore chosen as the campaign phrase. The line has multiple meanings. A literal reading asks the viewer if s/he would be willing to declare racist beliefs to the world by wearing them on a t-shirt as depicted in the campaign image. In colloquial Australian English the phrase means would you put up with/accept/tolerate something. So it challenges the community to be active in creating a GLBT community where everyone is accepted and respected. The call to action was for people who had witnessed or experienced racism in the GLBT community to report it either online or by phone in order to gather further data.

### Impact of discrimination on HIV prevention and care

Racial discrimination means isolating population groups from the broader gay community, and consequently compromises many key access points for HIV prevention and care information and services. This is particularly harmful for CALD communities, as they are more likely to be experiencing other challenges to accessing HIV prevention and care information, such as lower socio-economic status, visa issues, and cultural and language barriers.

The health issue addressed by this campaign is the detrimental psychosocial impact of perceived social and sexual racism within the GLBT community. Racial discrimination has been linked to a number of negative mental health outcomes, including psychological distress, anxiety, and depression (Hwang and Goto, 2008). This is particularly relevant given that health services and promotions that fail to acknowledge racial diversity can alienate and exclude CALD members from the GLBT community, contributing to poorer access to health services by these vulnerable populations.

### Development of the campaign

The campaign was developed by a diverse group of cross-project ACON staff, including representation from the Asian Project, the Aboriginal Project and the Anti-Violence Project among others, as well as community consultation and focus-testing. Funding was received through a Community Services Grant from the City of Sydney.

It was the first campaign addressing racism in the GLBT community executed by ACON. As a new campaign issue and one that is sensitive, it was important to put time into consulting thoroughly and developing ideas carefully. There were a number of potential campaign targets. The two main ones were perpetrators or 'victims' of racial discrimination. Recognising the complex and subtle nature of how racism plays out it was decided the campaign should encompass both. While the target audience was the dominant culture, it was important to ensure that in speaking to the target community it did not alienate or offend other communities and that reporting was encouraged.

While there was a lack of research on the issue, the anecdotal evidence and community support were strong. The community forum reinforced that there was a critical link in moving from anecdotal evidence to having quantitative data to work with.

A challenge experienced in developing the campaign was recruiting models from some community groups who expressed fear of physical retribution from their community if they represented themselves publicly as homosexual/supporting a homosexual campaign.

### Community responses

The campaign was launched in March 2008 in GLBT media. The campaign received strong community support throughout its development and execution with positive feedback received, requests for posters and interest from other community organisations. It did not, however, yield as many responses to the reporting tool as hoped for.

Over an eight month period there were 59 uses of the online reporting tool with 50 percent of users reaching the end of the online report. The most common reports were 'Negative comments' (64.7 percent), 'Exclusion/social isolation' (38.2 percent), 'Nasty looks and stares' and 'Jokes' (23.5 percent). Reports were also made of physical attacks (11.8 percent) and harassment eg. spitting, objects thrown, being followed (14.7 percent). The most common environments for racist incidents were public places, followed by clubs/bars/pubs, followed by the Internet.

### Lessons learnt

While attempting to capture the dynamics and complexity of racist incidents, the number of questions in the reporting tool appeared to be a barrier.

Despite these limitations to the responses gathered, the data did reveal discernable patterns with regard to the nature and location of racist incidents. These patterns have the potential to guide future work addressing racism in the GLBT community. From the findings, our recommendations include working with venue owners to reduce racist behaviours from their staff, further focus-testing with Caucasian men in future social marketing approaches that challenge racist behaviour, and investigating the relationship between the culture of gay inner Sydney and racism.

ACON is seeking funding to take this work further.

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# Regional Snapshot: Fiji's HIV response and Australia's contribution

By John Godwin

Social factors that contribute to vulnerability to STIs include a young, mobile population and taboos that constrain open discussion of sex and sexual health. Some conservative faith-based groups discourage promotion of condoms, particularly to young people.

## A low level, rising epidemic

Fiji has a low-level HIV epidemic, yet very high rates of STIs. There has been a steady rise in reported HIV cases, from a cumulative total of 68 diagnoses by 2000, to 182 by 2004 and 259 by 2007. Many other cases go undiagnosed. UNAIDS and WHO estimate the actual number of people living with HIV to be over 450 in 2008.<sup>1</sup> Very high levels of stigma and concerns about confidentiality are a disincentive to testing.

Virtually all cases are acquired sexually. Injecting drug use has not been a factor in Fiji's epidemic to date. Males (56 percent) and young people aged 20–29 years (45 percent) are predominantly affected. Eighty-one (81) percent of diagnoses are indigenous Fijian, 13 percent Indo-Fijian and 6 percent other races.<sup>2</sup>

The high incidence of STIs such as syphilis and gonorrhoea is a proxy indicator of unprotected sex in the community.<sup>3</sup> Chlamydia is endemic among pregnant women. Social factors

that contribute to vulnerability to STIs include a young, mobile population and taboos that constrain open discussion of sex and sexual health. Some conservative faith-based groups discourage promotion of condoms, particularly to young people.<sup>4</sup>

Condom use is very low, and the selling of sex for cash or other commodities or services is widespread. In 1996, selling sex for cash was reported by 4.9 percent of males and 13.3 percent of females.<sup>5</sup> A survey of police and military personnel in 2005 found that 5.8 percent of males reported having sex with female commercial partners in the last year, none of whom reported consistent condom use.<sup>6</sup> Only 19 percent of men had correct knowledge about HIV protection and transmission.

There is little data available about men who have sex with men and a reluctance to openly acknowledge male to male sex. One study of Fijian men who have sex with men found that 71 percent of 400 males reported that

their male partners self-identify as heterosexual and yet regularly have sex with men.<sup>7</sup> The stigma associated with homosexuality means that male-to-male sex may be under-reported as a factor in HIV transmission.

### **The national response and donor landscape**

Fiji's response to HIV is led by the National Advisory Committee on AIDS and its Secretariat within the framework of the *National HIV/AIDS Strategic Plan 2007–2011*. The Fijian Network of People Living with HIV (FJN+), Fiji Red Cross Society, and the University of the South Pacific are represented on the National Advisory Committee alongside Government.

Fiji's national response is situated within the broader context of the *Pacific Regional Strategy on HIV and Other STIs 2009–2013*. The Secretariat of the Pacific Community (SPC) plays a key role in implementing the Regional Strategy and has attracted significant donor support. AusAID and NZAID provide assistance for Strategy implementation through the Pacific Islands HIV and STI Response Fund. Prime Minister Rudd announced Australia's contribution to the Fund of \$30 million in 2008. The Fund is managed by SPC and provides funding to government and civil society organisations. Australia's donation to the Fund builds on a ten year history of AusAID support for HIV projects in Fiji and the Pacific.

Fiji was included in a regional grant (Round 2) from the Global Fund to Fight AIDS, TB and Malaria which provided funds until June 2008. The emphasis of the Global Fund regional project was on testing and treatment. At the time of writing, the Global Fund is considering its next round of funding for the region.

UN agencies including UNAIDS, WHO, UNFPA, UNICEF and ILO provide technical and financial support to Fiji's HIV response across

a wide range of policy and program support areas. UNAIDS has provided leadership initiatives targeting parliamentarians, faith-based groups and business. The International Labour Organisation is working with Fiji's Tripartite Forum on implementing a regulation which makes it compulsory for employers to implement HIV workplace programs. In 2008, the Fiji Australia Business Council and UNAIDS established the Fiji Business Coalition on HIV and AIDS to work with businesses on raising awareness and improving workplace policies and practices.

### **Fijian NGOs and community groups**

AIDS Taskforce Fiji and FJN+ are Fiji's two HIV-specific organisations, though there are many other organisations with some involvement in HIV. The NGO and community sector response is fragmented, and there is not a strong history of collaboration or coordination.

Fijian NGOs and professional groups active in the response to HIV include Reproductive Family Health Association of Fiji, the Fiji Red Cross Society, Pacific Counselling and Social Services, Fiji Association of Social Workers, Fiji Council of Social Services and Fiji Nursing Association.

Local groups working with sex workers are the SWAN Project and Sekoula Project. Equal Grounds Pasifik works with men who have sex with men. Women's organisations involved

in HIV include Women's Action for Change, Fiji Women's Rights Movement and Fiji Women's Crisis Centre. Faith-based organisations also play a role, including the Fiji Council of Churches and Pacific Community for Pastoral Care and Counselling.

International NGOs working with local partners include the International Planned Parenthood Association, Red Cross, Marie Stopes International, Oxfam, World Vision and World Council of Churches. Marie Stopes International Australia provides social marketing of condoms, education and outreach. Oxfam Australia is supporting local partner Women's Action for Change in implementing HIV prevention.

### **Australian NGO and research partnerships**

AusAID funds the HIV Capacity Building Program to link Australian organisations to partners in Asia Pacific. This program funds a consortium of Australian organisations to implement a number of projects in Fiji.

For instance, Scarlet Alliance is developing the capacity of Fijian sex workers to develop an autonomous network to advocate on health and justice issues. The network will help to

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Scarlet Alliance is developing the capacity of Fijian sex workers to develop an autonomous network to advocate on health and justice issues. The network will help to train health care workers on issues such as discrimination.

train health care workers on issues such as discrimination. Scarlet Alliance is also facilitating partnerships between existing services for sex workers so as to improve the quality of services.

The Albion Street Centre is working to strengthen the capacity of the Fiji School of Medicine and Fiji School of Nursing to improve standards of HIV and sexual health services through training, mentoring and clinical placements. This includes engagement with affected communities in development and implementation of training, including sex workers, men who have sex with men, people living with HIV and young people. Albion Street Centre is working with Scarlet Alliance to engage sex workers in this activity and teaching modules on stigma and discrimination are being developed.

The Australasian Society for HIV Medicine (ASHM) helped to establish the Oceania Society for HIV and Sexual Health Medicine (OSSHHM) in 2007. ASHM is partnering with OSSHHM to support its Fiji-based Secretariat to support health care workers in Fiji and other Pacific countries. This includes developing management skills and technical advice for policy development and delivery of clinical training programs.

Australia's National Serology Reference Laboratory (NRL) has provided training on testing and laboratory quality issues over a number of years to Fiji and is proposing to work with ASHM, Albion Street and OSSHHM to support the Fiji School of Medicine to better integrate laboratory services with clinical providers. NRL is partnering with the World Health Organization, the Secretariat of the Pacific Community and the Fiji Centre for Communicable Disease Control to phase in HIV rapid testing in the Pacific.

The School of Public Health and Community Medicine at UNSW is partnering with the Fiji School of Medicine and the University of South Pacific to develop a Pacific Institute for HIV and STI Research. The Institute will be based at the Fiji School of Medicine and strengthen Pacific-wide researchers' HIV social research skills.

The Pacific Sexual Diversity Network is a regional network of organisations addressing the needs and rights of men who have sex with men and other sexual minorities, including Fiji's Equal Ground Pacific. AFAO and ACON are partnering with the Network to build its capacity in leadership, human rights, research, management, policy and governance.

## Let's talk about sex

Fiji's turbulent domestic politics and vulnerability to the global economic downturn mean that much else is on the national agenda apart from HIV. The leadership of UN agencies, donors and the Secretariat of the Pacific Community are critical to ensuring Fiji's HIV response maintains momentum in volatile times. Australian organisations are playing a significant role as partners in this task and helping to build community-led responses. The establishment of the Pacific HIV and STI Response Fund is providing a timely injection of new resources.

But money alone won't be sufficient. Fiji also needs local leaders with the skills and commitment to address the complex social, cultural and political factors that still stand in the way of a comprehensive HIV and STI response. Above all, Fijian society will need to confront and address stigma and taboos associated with HIV, STIs and sexuality if the response is to move forward on a sustainable footing.

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Australian organisations are playing a significant role as partners in this task and helping to build community-led responses. The establishment of the Pacific HIV and STI Response Fund is providing a timely injection of new resources.



## *Unbearable Witness: how Western activists (mis)recognise sexuality in Iran* by Scott Long<sup>1</sup>

A review Andy Quan and Finn O'Keefe

Scott Long, researcher for Human Rights Watch, has had access to three years of research and 110 interviews on human rights abuses based on sexual orientation and gender identity in Iran.

It's likely you've seen this image: two young men, cloth over their heads, dead at a public hanging. Since 2005, we'd been told what happened, that these men have died for being gay in Iran. It's likely that emotions rose within us of disgust, anger, and fear. But what if this story is untrue or distorted – one that says more about how gay politics play out in the world today rather than what really happened?

Scott Long, researcher for Human Rights Watch, has had access to three years of research and 110 interviews on human rights abuses based on sexual orientation and gender identity in Iran. In March 2009 in *Contemporary Politics*, he published a hard-hitting and eloquent 17-page challenge to what has been accepted as common knowledge by many: that gays are executed in Iran.

The powerful image of young gay men brutally executed for their sexuality has been useful for some Western gay activists, brought attention to their groups, and traffic to their websites. It also promotes the idea that gays are the same around the world, though some meet unluckier ends.

But what really happened? Long describes two different cases and how they came to the attention of the world. The charges against two boys

publicly executed in 2005 were for the alleged rape ('sodomy by force') of a 13 year-old boy. In 2008, a 21 year-old was executed for a rape allegedly carried out on another boy when he was 13. There was no evidence that any of these individuals were gay, nor that there was any consensual sex. But gay groups, such as London's OutRage! Group and widely read bloggers such as Andrew Sullivan and Doug Ireland blared headlines of gay executions and called for letters to be written and petitions to be signed.

This coincided with general public fears of Islam – with the election of hard-line President Mahmoud Ahmadinejad in Iran – and local campaigns, such as OutRage!'s Peter Tatchell warning of

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Muslim fundamentalists as a threat to gay human rights in Britain. Those who doubted the interpretation of events were accused of being sympathetic to Iran. Long describes in detail this incredible set of stories and then grounds it in discussion of different types of gay activism: 'a politics of recognition' versus a 'politics of redistribution', exemplified in the battle for symbolic power (such as gay marriage) versus tangible security (such as protection against discrimination).

This story is relevant for the Australian HIV sector, I think, in that it asks us to interrogate how we use identities overseas and whose purpose do they serve? Are there global identities of gay man/MSM, person living with HIV, sex worker and drug user? Can we catch ourselves when we slip into the language of outrage but are not sure of

our facts? A broader issue for activists is the use of new media technologies like blogs, news websites and twitter to highlight causes, raise funds and lobby people to take action. It takes seconds for people to press send on a protest email and then forget about it, without engaging with the issue, debating, considering alternative viewpoints or thinking through the ramifications of their actions.

Scott Long's article has all the elements of my favourite writing, non-fiction or fiction: eloquence, intelligence, passion, and a challenge to how we perceive the world, or how it is being handed down to us. It addresses universal concerns of identity, social change, mortality, and meaning. As a human rights advocate, he points to the two young men who were killed for something that happened when they were children.

'They did not deserve this violence: they did not deserve to die.' Whether or not they were gay should not 'determine the limits of our caring'. And if they were gay, then their deaths 'deserve to be left to their own ... meaning, not fought over ... a continent away.' In the end, he returns to the horrifying images that have become famous world-wide, and concludes, '[T]he three years of desperate emotion over these pictures will stand ... as an embarrassing passage in the history of LGBT activism.'

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# WEB WATCH



Avert.org advertises itself as 'the world's most popular AIDS website'. It's not possible to know if this claim is true but it's not hard to imagine that it might be, when you look at the site. Avert is an excellent source of basic information about HIV and AIDS, with sound but comprehensible information about prevention, testing and treatment, the history and science of HIV, and the current state of the epidemic around the world.

The statistics section – with a helpful link on the home page – is particularly useful for journalists and students, with excellent statistics on the epidemic globally available at a glance. That said, the statistics for Australia don't add a great deal to NCECHR's *Annual Surveillance Report* and are slightly out of date – quoting the 2007 report.

Another disappointing aspect of the site from an Australian perspective is

that information about men who have sex with men is rather light on. While it does include statistics about MSM transmission where these are available – and it's true that in many places they aren't – the resources listed under 'gay and lesbian' are virtually non-existent. There are many excellent resources about gay men and HIV available but the site lists just one: a guide called *Young Gay Men Talking*. In fact, the lack of links to other sites is a real weakness of avert.org.

Young people appear to be the target audience of this site, with innovations such as 'the AIDS game' appearing on the home page. It's hard to imagine people who work in HIV taking time out to play the 'AIDS game' or complete the various other quizzes included in the site, but they make excellent learning tools for students. And for people at all levels seeking basic information about HIV, it's hard to go past avert.org.

they do not have the knowledge, skills or means to manage, and people for whom they may lack empathy. Acting as deterrents to access to early diagnosis, support and prevention and treatment services, discriminatory actions amount to unsound public health practice. They also constitute violations of human rights.

For HIV-positive people and people with AIDS, discrimination arises in the context of restrictions on international travel; barriers to employment; unequal access to education, medical care, or health insurance; and the many issues raised by 'routinised' HIV testing, including named reporting, involuntary partner notification, and breaches of confidentiality. These issues are obviously serious, and more than 20 years into the epidemic, they have not been fully resolved.

### **Discrimination and human rights**

Empirical evidence has clearly established that to uproot the pandemic involves attention to civil, political, economic, social and cultural determinants of vulnerability to HIV/AIDS, principles that are spelt out in the Universal Declaration of Human

Rights, which reminds us that 'All human beings ... by the mere fact that they are born human, have the right to an adequate standard of living,' which, among other things, includes a right to the highest attainable standard of health care.

The rights to equality and to be protected from discrimination are at the core of all International Human Right Treaties which translate the inspirational Universal Declaration into internationally binding obligations. These, together with other international treaties and declarations, provide states as much as they need to shape their policies and laws and be transparent and accountable nationally and internationally towards fulfilling their obligations in the context of HIV.

Examining the impact of discrimination on both health and human rights, it is apparent that every component of health policies and programs, and every human right can be affected by HIV-related discrimination, and the experience of those who suffer from discrimination can speak convincingly on these issues. Therefore, a rights-based response to HIV and related infections is the

right direction for combating stigma and discrimination.

A rights-based response calls for a strong focus on addressing discrimination and more broadly for a comprehensive approach which encompasses civil, political, economic, social and cultural rights. It emphasises building capacity and does not use human rights norms as a way to name violations after they occur but as a way to prevent violations from occurring in the first place and is based on implementation of one or several core rights concepts including non-discrimination, participation, accountability and transparency.

Anchoring HIV strategies in human rights can enrich the concepts and methods used to attain health objectives, by drawing attention to the legal and policy context within which interventions occur, as well as bringing in rights principles such as non-discrimination and the participation of affected communities in the design, implementation, monitoring, and evaluation of health systems, programs and other interventions. A human rights response to HIV also helps the state frame public policies, legislation and programs which recognise health and well being as the necessary ingredient and the resulting manifestation of societal progress.

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medication, at the right time every day, you may live for decades<sup>28</sup> and that '[t]here should be no doubt in the mind of the gaol authorities that this is the case. Those charged with the responsibility of caring for you whilst you are in prison should be alert to this fact'.<sup>29</sup> With respect, the judge's views on the health effects of prison and the process for Neal gaining treatment are rather sanguine. His Honour merely referred the written statement of Neal's doctor to the relevant prison where he will be placed. There was no formal process cited by the judge which guarantees the care and treatment of persons imprisoned with HIV.

### Conclusion

The end of the Neal trial was a welcome relief for many people anxious about the negative legal implications of the case for future prosecutions of HIV

transmission, and concerned about its stigmatising effect on people living with the disease. While the Neal case shows that the burden of living with HIV is a relevant factor in mitigating a custodial term, the sentence imposed carries mixed messages about access to care in prison; personal responsibility and sexual behaviour; the disclosure of HIV status to prospective sex partners; and the negative stereotypes judges continue to adopt when dealing with gay men and positive people.

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- 1 [2009] VCC 181 ('Neal').
- 2 Ibid para 8.
- 3 Ibid para 9.
- 4 See Roberts, B. 'HIV Conversion Party Shock', *Herald Sun*, 31 March 2007.
- 5 *Neal* para 9.
- 6 Ibid.
- 7 Ibid para 107.
- 8 While the judge refused to state a definite view on the stage the 'plea

- negotiations' over s 19A reached, this was the submission of Neal's lawyers: *ibid* para 107.
- 9 Reeders, D. (2008) 'Outcomes in Neal and Kuothe Cases', *Poslink*, 41, p.8.
- 10 *Neal* para 183.
- 11 *Ibid* para 152.
- 12 *Ibid* para 156.
- 13 *Ibid* para 156.
- 14 *Ibid* para 136.
- 15 *Ibid* para 121.
- 16 *Ibid*.
- 17 *Ibid* para 127.
- 18 *Ibid* para 122.
- 19 *Ibid* para 100.
- 20 *Ibid* para 101.
- 21 Weait and Azad makes arguments to this effect: see Weait, M., Azad, Y. (2005) 'The Criminalisation of HIV Transmission in England and Wales', *HIV AIDS Policy and Law Review*, 10, 2, p.1.
- 22 *Neal* para 18, 46.
- 23 *Ibid* para 158.
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- 25 See the discussion in Weait, M. (2007) *Intimacy and Responsibility: The Criminalisation of HIV Transmission*, London: Routledge.
- 26 *Ibid* para 157.
- 27 *Ibid* para 156.
- 28 *Ibid* para 92.
- 29 *Ibid* para 95.

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that aim to raise general awareness of HIV and specific awareness of the issues associated with people living heterosexually with HIV among healthcare practitioners.

In addition to client support, health promotion and training, the Heterosexual HIV/AIDS Service is involved in the Straightpoz research study. It also continues its advocacy role through committee representation, ensuring that the specific issues related to people living heterosexually with HIV are on the agenda for other services in policy and service development in metropolitan and regional areas of NSW.

In our opinion, the misperception and statements about the numbers of heterosexual people living with HIV being negligible in Australia, only increases the stigma experienced by the growing number of heterosexuals who are living with HIV, and reduces the demand for greater public awareness and visibility. While our role is to support heterosexuals living with HIV, their families and carers, our clients often raise the issues about prevention and the need for greater awareness “out there”. We believe there needs to be acknowledgement through the media, service providers and within the HIV sector that the number of heterosexuals with HIV is growing yearly as the figures reflect, to dispel the idea that HIV amongst heterosexuals is not a growing issue here in Australia. Heterosexuals living with HIV tell us their concerns about the increasing risks to the heterosexual community, who do not see HIV as their issue, and don't identify with it.

In 2009 in NSW, HIV does affect the lives of many ‘straight’ people, their families and carers. With a sense of belonging in the HIV community considered important, and HIV being a life changing event, finding good support is often crucial (getting

support can be daunting); needs vary for each individual, often because of the personal identity that one holds.

A better understanding of the issues for heterosexual people with HIV may validate and de-stigmatise the experience, for those heterosexuals who are currently living with HIV, who sometimes describe feeling they are part of a minority within a much larger minority. The heterosexual experience of HIV, if spoken about more, may demystify and thereby enhance our ability to cater for specific needs within the diverse HIV community.

The ‘Pozhets’ Service wants this scenario ... for 2009 and beyond:

*A heterosexual person receiving news that they're HIV-positive knows from the media that HIV affects anyone; knows they will probably live a healthy life; knows they're not alone and that there are other heterosexuals with HIV, knows where to get support, and lastly, knows they can find someone to talk to.*

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6 Ibid iii.

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8 Ibid iv

9 Ibid iv

**Kate Reakes and Pene Manolas are from PozHet, a NSW heterosexual HIV/AIDS Service.**

With a sense of belonging in the HIV community considered important, and HIV being a life changing event, finding good support is often crucial (getting support can be daunting); needs vary for each individual, often because of the personal identity that one holds.

Whereas moral panic and stigma are concerned with the reproduction of ideology and social order – quite abstract, high level structures – the American sociologist Howard Becker’s concept of ‘moral entrepreneurialism’ captures the potential for deliberate/opportunistic deployment of panic and stigma to advance a particular social agenda.<sup>9</sup> Recent examples include the children overboard affair and the War on Terror. To these, I would add the ‘barebacking and bug-chasing’ memes, which spread like wildfire in the mainstream and gay community media, out of all proportion to their actual incidence in ‘real life’.

In a conference paper, I have described barebacking and bug-chasing as ‘images in a jurisprudence of desire’ – a justification for intervening in gay male sexual culture by representing unprotected sex in relation to deliberate/reckless HIV infection.<sup>10</sup> Criminal prosecutions of HIV-positive people for onward transmission are the logical consequence of this process, but it’s the logic that matters, not the outcome; criminalisation may be seen as ‘collateral damage’, especially in light

of its unintended consequences (such as giving negative men a false sense of security).

### Governmental

One of the most seductive ideas in recent educational discourse has been the prospect that we can create or harness a ‘cultural norm’ against barebacking or in favour of condom use. Citing peer pressure against smokers, public health researcher Ronald Bayer recently asked a provocative question: can ‘good’ stigma be used to discourage behaviours that are harmful to individual and public health?<sup>11</sup>

In relation to queer sex, however, this approach can only fail. By the time two men have sex, we have already had to transgress so many cultural norms, about gender, desire and the male body, our sexual relations are a physically embodied critique of social normativity – a fact simultaneously acknowledged and dismissed in the stereotype of gay men as inherently transgressive or ‘naughty by nature’.

In response to Bayer, Scott Burrell points out that regardless of severity, stigma has an objective of

dehumanisation at its core (‘us-and-them thinking’ in the Link and Phelan model) and argues this has no place in governmental responses to social problems of any kind.<sup>12</sup>

### Solutions

Around Australia, successive state/territory and National HIV/AIDS Strategies have acknowledged the central importance of tackling stigma and discrimination to create a supportive environment for HIV prevention and the promotion of positive health. It is time to identify stigma reduction as a priority for well-conceived, properly-funded programmatic action – and here’s what we could do to start:

- By adopting a shared definition and language around stigma, using the insights offered by Link and Phelan and Parker and Aggleton, we can define and offer solutions based on what stigma isn’t;
- Narratives like ‘Dean’s Story’ on the VAC/GMHC *Staying Negative* campaign website<sup>13</sup> illustrate the social learning process that HIV-negative men can undergo to overcome their fear of HIV and practice of stigma discrimination;
- A literature review of stigma solutions, undertaken for a new AFAO campaign on the topic, suggests personal contact with people living with HIV enables HIV-negative men and the broader community to ‘triangulate’ (critically evaluate) negative stereotypes distributed through media and online;
- Personal and public disclosure of HIV status benefits HIV-negative men by increasing their cognitive availability of

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the prevalence and possibility of HIV infection, and reduces the impact of negative cultural stereotypes.<sup>14</sup> It could therefore be understood and promoted as an act of courage and a gift from people living with HIV to their communities;

- Campaigns, outreach and peer education should acknowledge that change happens slowly and focus on building skills – for positive men, around framing and timing disclosure, and for negative men, around acknowledging their feelings and responding sensitively to disclosure;
- Community-based research and activism against sexual racism offer a model for HIV stigma reduction in online gay chat and profile sites. (*Sexual racism* is the stigmatisation of Asian men as sexual and romantic partners, and expression of racial microaggression towards them<sup>15</sup>). By pointing out that it *doesn't cost users anything* to choose positive expressions of desire and preference, this approach highlights the racism and aggression underlying the insistence on saying 'No Asians', refuting the claim that it's 'just preference', a value-neutral right to choose; and
- On a day to day basis, AIDS Councils and PLWHA organisations need to engage with and 'talk back' to the promotion of stereotypes about gay men and HIV in the media, not by making the factual point that irresponsible people living with HIV or gay barebackers are rare – since facts are never allowed to get in the way of a good story – but by offering actual name-and-face counter-narratives of altruistic and responsible gay/poz men.

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Personal and public disclosure of HIV status benefits HIV-negative men by increasing their cognitive availability of the prevalence and possibility of HIV infection, and reduces the impact of negative cultural stereotypes.

# TREATMENT BRIEFS

## 'Treatment as prevention' must not violate human rights, conference told

The expansion of HIV testing programs and the advocacy of universal testing and treatment of those who test positive as a means of prevention must not violate the human rights of target populations, the Fifth IAS Conference on HIV Pathogenesis, Treatment and Prevention was told in Cape Town.

Representatives from the organisations Human Rights Watch and the AIDS and Rights Alliance of Southern Africa (ARASA) told testing advocates to ensure that testing is not coercive, that it is linked to treatment provision and treatment education, that the peer counsellors who perform testing understand confidentiality and informed consent, and that those who test positive are not subjected to ostracism within their communities.

The background to a series of seminars and discussions on the way forward for 'treatment as prevention' was a political disagreement among the HIV advocacy and public health communities dating from last year.

In 2008, two mathematical models appeared in HIV journals showing that universal treatment of people who test positive for HIV would reduce the epidemic in the worst-affected countries by 90 to 95 percent by the year 2050.

The first, by Julio Montaner's team (Lima) at the British Columbia Centre for Excellence in HIV/AIDS, found that two-thirds of infections in the province would be averted if all patients started treatment when their CD4 cell count was around 350 cells/mm<sup>3</sup>.

The second exercise (Granich) was published in *The Lancet* last November. This model found that achieving the

somewhat utopian goal of universal HIV testing and treatment for everyone diagnosed HIV-positive would reduce HIV incidence from 2 percent a year to 0.1 percent a year within ten years and would reduce prevalence by 95 percent by 2050.

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— Gus Cairns, *Aidsmap*

## Boosted and unboosted atazanavir maintain viral suppression equally well

Unboosted atazanavir (*Reyataz*) taken once-daily as part of a combination antiretroviral regimen can keep viral load undetectable in patients who discontinue ritonavir, researchers reported at the Fifth International AIDS Society Conference on HIV Pathogenesis, Treatment, and Prevention in Cape Town, South Africa.

In the ARIES trial, more than 500 treatment-naïve HIV patients started a regimen of boosted atazanavir/ritonavir (300/100 mg) taken once daily plus the fixed-dose abacavir/3TC combination pill (*Kivexa*). The open-label study had statistical power to show whether unboosted atazanavir was non-inferior to the boosted drug.

At the end of 84 weeks, in an intent-to-treat analysis, 86 percent of patients taking unboosted atazanavir had viral load below 50 copies/ml compared with 81 percent of those taking ritonavir-boosted atazanavir, a difference that did not reach statistical significance ( $p=0.140$ ). Looking at viral load below 400 copies/ml, the corresponding rates were 92 percent vs 86 percent, which was a significant difference ( $p=0.036$ ).

The researchers did an analysis that separated people with high and low baseline viral load (above or below 100,000 copies/ml), and again found that similar proportions of patients taking unboosted and boosted atazanavir had viral suppression below 50 copies/ml at the end of the study.

Only one person in the unboosted atazanavir arm experienced confirmed virological failure, compared with seven in the atazanavir/ritonavir arm.

Treatment was well-tolerated by patients in both arms of the study. Similar proportions of patients in the unboosted and boosted atazanavir arms experienced moderate-to-severe side-effects (26 percent in both groups after the initial 36 weeks, then 10 percent vs 14 percent during the next 48 weeks). The frequency of hyperbilirubinaemia (a non-dangerous, but cosmetically distressing side-effect of atazanavir caused by a build up of bilirubin and involving a yellowing of the eyes and skin) was more than twice as common in the atazanavir/ritonavir arm (4 percent vs 10 percent).

Compared to lipid values at the time of randomisation, median total cholesterol fell during the next 48 weeks in patients taking unboosted atazanavir, whilst it increased slightly in the boosted atazanavir arm. Triglycerides likewise decreased more in the unboosted atazanavir arm. The investigators concluded that boosted (atazanavir with ritonavir) and unboosted atazanavir demonstrated similar efficacy regardless of baseline viral load, but patients who simplified therapy by stopping ritonavir had a more favourable lipid profile.

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— Liz Highleyman and Michael Carter, *Aidsmap*

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Diary



Australian Government

# YOU COULD HAVE AN STI WITHOUT EVEN KNOWING

You might think your partner is safe, but with many sexually transmissible infections the symptoms don't show for months or even years. If you have had unprotected sex, see your doctor about getting tested. Using a condom is the best way to avoid getting or spreading infections like chlamydia, syphilis, gonorrhoea and HIV.

**STIs ARE SPREADING FAST**  
**ALWAYS USE A CONDOM**

[www.australia.gov.au/STI](http://www.australia.gov.au/STI)