

# HIV

AUSTRALIA

What?

if

only?

## WOMEN AND HIV: BEHIND THE DATA

VOLUME 9 • NUMBER 4

**Editors** Finn O'Keefe and Linda Forbes

**Treatments Editor** Jason Appleby

**Design + Production** Ascending Horse [www.ascendinghorse.com](http://www.ascendinghorse.com)

**Correspondence**

*HIV Australia* C/- AFAO, PO Box 51 Newtown NSW 2042 Australia

**Telephone** +61 2 9557 9399

**Facsimile** +61 2 9557 9867

**Email** [editor@afao.org.au](mailto:editor@afao.org.au)

**Website** [www.afao.org.au](http://www.afao.org.au)

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**AFAO is the national federation for the HIV community response, providing leadership, coordination and support to the Australian policy, advocacy and health promotion response to HIV/AIDS. Internationally, AFAO contributes to the development of effective policy and programmatic responses to HIV/AIDS at the global level, particularly in the Asia Pacific region.**

AFAO's aims are to:

- Advocate on behalf of its members at the federal level, thereby providing the HIV 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;
- Develop and formulate policy on HIV 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 and its effects.

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**A note from the editors**

You will note that *HIV Australia* has a striking new look for 2012 – a black and white format. The cost efficiencies this provides will allow us to maintain a focus on quality content, while also securing the future of the magazine as a free print publication (an increasing rarity in this day and age!)

Results from the 2011 *HIV Australia* Readers' Survey, indicated that readers appreciate receiving *HIV Australia* in printed form; over half of the survey respondents said that they share each copy of the magazine with one or more person. You can read more results from the survey at [www.afao.org.au](http://www.afao.org.au). In 2012, we will continue to offer additional content online not available in the printed publication.

We are grateful for all the passionate feedback and support we received from you throughout the last year. We hope that you will continue to provide us with input, feedback and suggestions for content in subsequent editions by writing to us at [editor@afao.org.au](mailto:editor@afao.org.au)

**This edition of *HIV Australia* unpacks figures and facts pertaining to the HIV epidemic among women, both in Australia and internationally. Authors explore specific issues that affect the lives of HIV-positive women, and ask why some topics remain under-explored.**

**Cover image** *What if only* by Michael Coyne. Taken from 'A Body of Knowledge', an exhibition coordinated by Positive Women Victoria, with thanks to the Australia Council.

The exhibition featured works produced by photographer Michael Coyne and writer Graham Pitts, working with members of Positive Women Victoria. The exhibition provided an opportunity for HIV-positive women to be more visible and express their thoughts and feelings. It is hoped that the exhibition will be able to tour Australia in the coming years. For further information please visit [www.positivewomen.org.au](http://www.positivewomen.org.au)

***HIV Australia* online includes additional content not published in the printed edition. Read more of *HIV Australia* at [www.afao.org.au](http://www.afao.org.au)**

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*HIV Australia*  
C/- AFAO, PO Box 51, Newtown NSW 2042 Australia

<b>Australian news</b>	<b>4</b>	<b>Anti-trafficking, sex workers' rights and HIV prevention</b>	<b>27</b>
<b>International news</b>	<b>5</b>	JULES KIM argues that the global anti-trafficking movement has created an environment that impinges upon sex workers' rights	
<b>Women and HIV in Australia: an overview</b>	<b>6</b>		
SALLY CAMERON presents a summary of current statistics on women living with HIV in Australia			
<b>Beyond the data: distinct features and experiences of women living with HIV in Australia</b>	<b>8</b>	<b>Transgender women and HIV: a footnote to the epidemic</b>	<b>30</b>
RACHEL KOELMEYER, KARALYN MCDONALD and JEFFREY GRIERSON shed light on the experiences of women living with HIV in Australia		ABIGAIL GROVES examines the history of transgender women and HIV in Australia, finding 'a paucity of research'	
<b>Women and HIV: 30 years on. Where to from here?</b>	<b>11</b>	<b>Rethinking 'equality': The gendered experience of HIV risk-taking and prosecutions for HIV exposure and transmission</b>	<b>33</b>
JANE COSTELLO explains why female activists are angry about a lack of participation opportunities for HIV-positive women in global responses to HIV		SALLY CAMERON explores the reasons behind the disproportionate number of female witnesses in Australian criminal cases involving HIV transmission or exposure	
<b>'You don't grow another head': the experience of stigma among HIV-positive women in Australia</b>	<b>14</b>	<b>The Hon. Kay Hull, MP: a champion for the partnership response to HIV</b>	<b>37</b>
KARALYN MCDONALD discusses the layers of stigma associated with pregnancy and motherhood experienced by women living with HIV		GRAHAM BROWN and SENATOR LOUISE PRATT pay tribute to the work of a political stalwart	
<b>Experiences of women from culturally and linguistically diverse backgrounds living with HIV: children and parenting</b>	<b>18</b>	<b>Book review: 100 Dolls, Countless Hearts – Stories of childhood from Multicultural Australia</b>	<b>39</b>
HENRIKE KÖRNER presents extracts from interviews with HIV-positive women about the experience of migration, HIV and parenting		JILL SERGEANT discovers how the Uthando Project is crafting a response to HIV	
<b>Navigating the journey: sharing the stories of HIV-positive women</b>	<b>21</b>	<b>Web Watch</b>	<b>40</b>
JAMES MAY profiles a new initiative from Positive Women Victoria that explores the value of sharing personal experiences		<b>Treatment briefs</b>	<b>41</b>
<b>Women, HIV and ageing: some specific challenges</b>	<b>24</b>		
MIA DAWSON highlights the physical and emotional aspects of ageing experienced by HIV-positive women			

*HIV Australia* welcomes submissions from interested authors. To submit an article or report for consideration, email [editor@afao.org.au](mailto:editor@afao.org.au)



## AUSTRALIA

### Need for Australia to exercise global leadership in the fight against HIV

The Australian Federation of AIDS Organisations (AFAO) and RESULTS International have issued an urgent call to the Australian Government to prioritise its financial commitment to the Global Fund, or risk jeopardising crucial advances in HIV treatment and prevention.

In a joint letter addressed to Foreign Affairs Minister Kevin Rudd, the two community organisations called on the government to bring forward its 2011–2013 funding commitment of \$170 million, while also committing to a one-off funding top-up. The call follows the Global Fund's decision last November to cancel Round 11 funding, thus preventing funding of new programs or scale-up opportunities until 2014.

The Global Fund celebrated its ten year anniversary in 2012. Over the last ten years it has been the dominant funder of programs against HIV, tuberculosis and malaria worldwide, saving 100,000 lives every month. But the recent economic downturn has seen a number of donor countries either scale back or fail to deliver on their commitments to the Global Fund, placing its future at serious risk.

'In 2011, all United Nations members adopted a target of a 50% reduction in HIV transmission and 50% of people with HIV being on treatments by 2015. Without the Global Fund, this target is impossible,' explains Rob Lake, Executive Director of AFAO.

### Bill Bowtell receives Order of Australia

As part of the Australia Day honours list 2012, public health expert Bill Bowtell

was made an Officer of the Order of Australia (AO) in recognition of his 'significant contributions to public health and for his role in developing and implementing of policy and programs supporting HIV/AIDS awareness and prevention'.

Bill Bowtell is recognised as an architect of Australia's successful and well-regarded partnership response to HIV. In 1984, he was senior adviser to the Australian health minister, Neil Blewett, and played a significant role in the introduction of the Medicare health insurance system – a social innovation that saw healthcare delivered to all Australians based on equity of access. Between 1994 and 1996, he was senior political adviser to the former Australian Prime Minister, Paul Keating.

Since 2005, Mr Bowtell has been Director of the HIV/AIDS Project at the Lowy Institute for International Policy and since 2009, the Executive Director of Pacific Friends of the Global Fund. He has been a Member of the Ministerial Advisory Committee on Blood Borne Diseases and Sexually Transmissible Infections since its inception, and is a former President of AFAO. He maintains a close interest in the potential impact of the HIV/AIDS epidemic internationally, and particularly within Asia and the Pacific. He has written and broadcast extensively on HIV, and continues to debate key issues in the media and at international and Australian conferences and seminars.

### Three HIV/sexual health conferences to come to Melbourne in October 2012

Australia will host the 13th International Union against Sexually Transmitted Infections (IUSTI) World Congress this year. The event will also incorporate the 2012 Australasian Sexual Health Conference, and will be held back-to-back with the 24th Australasian Society for HIV Medicine (ASHM) HIV/AIDS Conference. The three events will take place at the Melbourne Convention and Exhibition Centre in October 2012.

The IUSTI World Congress is an annual event that attracts a wide range of international speakers and guests. IUSTI Congress Convenor Professor Christopher Fairley explains that, 'Following Australia's success in winning the bid to host the IUSTI World Congress in 2012, we saw this as an ideal opportunity to combine the 2012 World IUSTI Congress with the 2012 Australasian Sexual Health Conference. We are very excited about this opportunity, as the combined program will allow for an increased focus on international issues while still maintaining a focus on issues specific to the Australian context.'

The combined events will see a number of distinguished Australian and international keynote speakers coming to Melbourne in October 2012. Conference organisers are expecting around 200–300 international delegates in attendance for IUSTI 2012, in addition to around 550 Australian delegates that attend the Australasian Sexual Health Conference each year.

The 13th IUSTI World Congress will be held 15–17 October 2012. The 24th Australasian HIV/AIDS Conference will be held 17–19 October.

For further details see [iusti2012.com](http://iusti2012.com) and [hivaidsconference.com.au](http://hivaidsconference.com.au)

### HIV organisations co-locate

Two organisations governed by people living with HIV have announced relocation in 2012. After 20 years on Oxford Street, Darlinghurst, Positive Life NSW will move to 414 Elizabeth Street, Surry Hills in March, co-locating with other NSW-based HIV organisations including ACON and The HIV/AIDS Legal Centre (HALC).

Positive Women Victoria also recently re-located from Melbourne's CBD, now residing alongside Straight Arrows and PLWHA Victoria, at Coventry House, Suite 1, 111 Coventry Street, Southbank.

The co-location of a range of state-based HIV organisations will provide greater collaborative opportunities and easier access for clients using multiple services.



## INTERNATIONAL

### Protests against India Free Trade Agreement

In the lead up to the EU–India Summit, over 2,000 people living with HIV and health activists staged large protests in the streets of New Delhi, calling on the Indian government to defend generic HIV medicines in Free Trade Agreement (FTA) negotiations at the Summit. The protests were part of global week of action leading up to the Summit, which included letters of advocacy, rallies, and online actions. Similar protests were also staged in Nepal, Malaysia, the UK, South Africa, and Cameroon.

India produces quality affordable generic medicines that international governments, United Nations (UN) agencies and non-government organisations (NGOs) rely on to treat people across the developing world. Eighty percent of people living with HIV in developing countries receive generic antiretroviral medications produced in India, and over 90% of paediatric HIV medicines are supplied by Indian generics. India's generics have reduced the prices of antiretrovirals by more than 99%, from US\$10,000 per person per year in 2000 to approximately \$150 today.

If India agrees to proposed intellectual property provisions, this will dramatically restrict affordable treatments access for people living with HIV in developing countries. Existing trade rules already limit the production of generic versions of new medicines, but the EU–India FTA threatens to make this situation even worse by creating new barriers.

Speaking at the protest, Mundrika Gahlot of the Delhi Network of Positive People said, 'Whether we get to live or die should not be up to trade negotiators ... We're all here today with one clear message to India and the EU: Don't trade away our lives.'

### South Africa to produce generic ARVs by 2016

The South African government has entered into a partnership with a pharmaceutical company that will allow it to manufacture ingredients used in antiretroviral (ARV) drugs locally. South Africa is the largest consumer of antiretrovirals in the world and spends 4.2 billion rand (AUS\$509 million) a year on HIV medication. This new venture will allow the country to produce its own generic medication and reduce spending.

'The project is in line with the plans of the South African government to address HIV and AIDS through the local and cost effective production of antiretroviral drugs,' said Science and Technology Minister Naledi Pandor.

There are currently 5.58 million people living with HIV, approximately 11% of the South African population, according to data from the Actuarial Society of South Africa (ASSA). Of these people, five million (89%) are adults aged 20 to 64 years while 2.93 million (53%) are women of child-bearing age (15–49 years). Youth aged 15 to 24 years account for 731 000 (13%) of those living with HIV, and children aged 14 years and below account for 454,000 (8%).

The start of the construction of the project has been set for 2013 and the company is expected to start producing antiretrovirals by 2016.

### Call for the greater involvement of women at AIDS 2012

The XIX International AIDS Conference (AIDS 2012) recently announced the 15 plenary speakers who will present at this year's event, to be held July 2012 in Washington. Following the announcement, Alice Welbourn, HIV-positive activist and member of the ATHENA Network steering committee, has written to the conference organisers, the International AIDS Society (IAS), criticising the lack of involvement of HIV positive-women in the proceedings.

As Poz.com reports, the letter to the IAS pointed out that, despite the global HIV pandemic disproportionately affecting women, there were 'no women living openly with HIV; no young women; and no women of color from North America' on the program. The letter also stated that none of the participants announced in the IAS press release were identified as people living with HIV.

On its conference website the IAS states that one of the conference principles is to 'ensure gender equality in representation at all levels of the planning and in the implementation of the conference'. Poz.com has critiqued the plenary announcement as being contrary to the GIPA principles (Greater Involvement of People living with HIV/AIDS), which the IAS supports as part of its mandate.

At press time, the full program for AIDS 2012 was still under development, with further details to be announced on the conference website [www.aids2012.org](http://www.aids2012.org) in the coming weeks.

# HIV AUSTRALIA

## 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)

# WOMEN AND HIV IN AUSTRALIA: AN OVERVIEW

By Sally Cameron

This article provides a brief snapshot of recent data regarding women and HIV in Australia. Information is drawn primarily from the 2011 *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia Annual Surveillance Report*. For access to the report, as well as HIV datasets and slide sets, visit the Annual Surveillance page on the Kirby Institute for infection and immunity in society website: [http://www.med.unsw.edu.au/NCHECRweb.nsf/page/Annual Surveillance Reports](http://www.med.unsw.edu.au/NCHECRweb.nsf/page/Annual%20Surveillance%20Reports).

## Number of women living with HIV in Australia

By 31 December 2010, women comprised 9% of the estimated 21,391 people living with diagnosed HIV in Australia (Table 1).<sup>1</sup>

**Table 1** Women as percentage of total number of people diagnosed with HIV in Australia

Women	Men	Total <sup>2</sup>
1,984	19,407	21,391

Relatively few of the people in Australia living with HIV are women because HIV continues to be primarily transmitted through sexual contact between men. From 2006 to 2010:

- 66% of HIV diagnoses were among men who have sex with men
- 25% of new HIV diagnoses among men and women were attributed to heterosexual sexual contact
- 3% of new HIV diagnoses among men and women were attributed to injecting drug use

- exposure was undetermined in 7% of diagnoses.

## HIV diagnoses among women in Australia

In 2010, adult/adolescent women comprised less than 14% of the 1,043 people newly diagnosed HIV-positive<sup>3</sup>; a low proportion which is relatively consistent with diagnoses over the last decade (Table 2).

Over the past decade (2001–2010) the number of women newly diagnosed with HIV has risen substantially; there were approximately 44% more women diagnosed in the period from 2006–2010 than in the period from 2001–2005.

## Women contracted HIV through a variety of routes

Most women living with HIV have been infected as a result of heterosexual sex, either in Australia or overseas (most commonly in high HIV prevalence countries). Between 2001 and 2010, less

than 10% of women reported injecting drug use or having a sexual partner who injected drugs as the source of their HIV infection. In that same decade, the source of HIV infection was not recorded for approximately 10% of women diagnosed with HIV.

Women tended to be a few years younger than men when diagnosed with HIV infection

The reasons for this age discrepancy (Table 3) have not been fully explored but are likely to be the result of a combination of factors including issues relating to sexuality, and the intersection of gender and sexual activity.

## HIV and Aboriginal and Torres Strait Islanders

Women comprised a higher percentage of new HIV diagnoses among Aboriginal and Torres Strait Islander people, than did 'women' as a percentage of all people newly diagnosed with HIV (Table 4).

When considering recent trends in the rates of HIV diagnoses in the Aboriginal and Torres Strait Islander population it is important to note that the total number of diagnoses among Aboriginal and Torres Strait Islander people is small, and may reflect localised occurrences rather than national patterns.

Between 2006 and 2010, Aboriginal and Torres Strait Islander cases also differed from non-Indigenous cases, excluding cases from high prevalence countries, in that women comprised a far higher proportion of infections: 21.4% of Aboriginal and Torres Strait Islander cases, compared to 8% of non-Indigenous cases, were women.

The higher percentage of women with HIV infection among Aboriginal and Torres Strait Islander people may reflect the predominance of different modes of transmission. While sexual contact between men remained the most frequently reported route of HIV transmission in Aboriginal and Torres Strait Islander cases, it was less common than in non-Indigenous cases. Injecting drug use was a more frequent

**Table 2** Newly diagnosed HIV infection among women (Australia 2001–2010)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
<b>Number of women</b>	93	88	84	125	91	142	132	140	135	143
<b>Women (% of all diagnosed)</b>	12.1%	10.3%	9.6%	13.7%	9.5%	14.2%	12.7%	13.9%	12.8%	13.8%

**Table 3** Newly diagnosed HIV infection – by age<sup>4</sup>

Median age (yrs)	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Median 2001–2010
<b>Male</b>	35	35	36	37	37	38	38	37	37	37	37
<b>Female</b>	29	32	31	31	32	31	32	31	32	31	31

**Table 4** Newly diagnosed HIV infection<sup>5</sup>

2001–2010	All diagnoses	Indigenous diagnoses
<b>Adults/adolescents diagnosed</b>	9,475	207
<b>Adults/adolescent women diagnosed</b>	1,173 (12%)	56 (27%)

form of transmission among Indigenous cases than non-Indigenous cases.

### Testing and late diagnoses

Australian surveillance data records whether HIV infection is newly acquired at the time of diagnosis (measured as ‘acquired in the previous 12 months’). Newly acquired HIV infection was diagnosed most frequently among men who have sex with men (MSM), clearly indicating continuing HIV transmission in this risk group (Table 5). (Newly acquired HIV provides an indication of when an infection was acquired. Compared to MSM, relatively few women in Australia have a pattern of regular HIV testing. As a result, women are less likely to be identified among newly acquired HIV infections.)

Surveillance data also records cases where individuals are diagnosed late in their HIV infection<sup>6</sup>, i.e. where HIV has already had a significant impact on an individual’s immune system. Approximately 17% of people testing positive for HIV infection between 2006 and 2010 were diagnosed late in their HIV infection, with those who had acquired HIV through heterosexual

contact or injecting drug use far more likely than MSM to be diagnosed late (Table 6).

Late diagnosis partially reflects the contexts in which people become infected with HIV and their reasons for having an HIV test. According to *HIV Futures 6*<sup>7</sup>, women were less likely to have an HIV test as the result of routine health screening than gay or bisexual men. It is likely gay and bisexual men ask for HIV testing in routine health screen as a result of their risk activity and their awareness of HIV infection risk. Women who tested HIV positive were more likely than gay, bisexual men or heterosexual men to have had their HIV test because a partner had tested positive (Table 7).

**Table 6** Late diagnoses, 2006–2010

Exposure category	2006–2010	
<b>MSM – late diagnoses</b>	438	13%
<b>Heterosexual contact – late diagnoses</b>	353 (141 women)	32% (26% of women)

**Table 7** Reason for HIV test

	Women	Heterosexual men	Gay or bisexual men
<b>Routine health screen</b>	12.7%	12.5%	17.7%
<b>Partner tested positive</b>	18.2%	5.4%	7.4%

**Table 5** Newly acquired HIV diagnoses by transmission type

2006–2010	MSM	Heterosexual	Injecting drug use	Other/undetermined
<b>HIV diagnoses</b>	3,401 (66%)	1,303 (25%)	131 (3%)	342 (7%)
<b>Diagnoses of HIV acquired during previous 12 months</b>	1,276 (86%)	149 (10%)	13 (1%)	43 (3%)

### References

- 1 At 31 December 2010.
- 2 From Table 6.1.1 Estimated number of people living with diagnosed HIV infection in 2010 by State/Territory of HIV diagnosis and sex.
- 3 Note: this data does not reflect the year in which individuals were infected but only the year in which they were diagnosed.
- 4 From Table 1.1.1.
- 5 From Table 1.1.1.
- 6 Measured by the CD4+ cell count of less than 200 cells/μl at HIV diagnosis.
- 7 The *HIV Futures 6* survey was completed by 1,106 HIV positive people including 81 women (comprising 7.4% of respondents).

**Sally Cameron is a consultant and former policy analyst at AFAO.**

# BEYOND THE DATA: DISTINCT FEATURES AND EXPERIENCES OF WOMEN LIVING WITH HIV IN AUSTRALIA

By Rachel Koelmeyer, Karalyn McDonald and Jeffrey Grierson

## Introduction

In Australia, women represent a small proportion of the total population of people living with HIV. As of 31 December 2010, a total of 21,391 people were estimated to be living with a diagnosed HIV infection in Australia, of whom 1,984 (9.3%) were women.<sup>1</sup> Due to Australia's large size and moderate population, the small number of women living with HIV are widely dispersed, often isolated and almost invisible within the epidemic.<sup>2</sup>

The *HIV Futures* studies, comprising six national cross-sectional surveys of people living with HIV in Australia, have been conducted every two to three years since 1997; the surveys are a key resource that sheds light on the experiences of women living with HIV in Australia.<sup>3-8</sup> This article describes some of the main features of the experiences of women

living with HIV in Australia, based on the *HIV Futures* studies and in-depth interviews with HIV-positive women conducted by Dr Karalyn McDonald.<sup>9-10</sup> The article focuses on areas in which women have been found to have a different experience of living with HIV, when compared with the predominant group of HIV-positive people in Australia – homosexually active men.

## Characteristics of women living with HIV in Australia

In 2009, the median age of women living with HIV was 43.5 years (range: 21 to 74 years).<sup>11</sup> Most survey respondents reported their sexuality as heterosexual (85.9%) and just over half (52.9%) reported being in a regular relationship—a third of whom also reported that their partner is HIV-positive.<sup>12</sup> Women living with HIV reside in all states and territories in

Australia; however, the vast majority live in New South Wales, Victoria, Queensland and Western Australia (90.8%).<sup>13</sup> Women living with HIV are more likely than gay/bisexual men living with HIV to reside in outer suburban or regional locations.<sup>14</sup> While just over half of HIV-positive women (52.0%) report being in paid employment, an alarming number are estimated to be living below the poverty line (49.6%).<sup>15</sup>

The vast majority of women living with HIV report contracting HIV through heterosexual sexual contact; injecting drug use and receipt of infected blood products are the other most common means through which women living with HIV report becoming HIV-positive. The median age of women at the time of their HIV diagnosis is 30 years.<sup>16</sup> At the time of testing positive, the predominant reasons why women underwent HIV testing were: becoming ill (30.2%), because their partner tested positive (17.1%), or due to a particular risk episode (12.9%). Women are more likely than homosexually active men to be diagnosed late, when their CD4 cell count is <200 cells/μL.<sup>17</sup>

## Importance of motherhood and reproductive health issues

Over time, parenthood and family have ranked consistently highly as important components of identity in women living with HIV, much more so than the role that being HIV-positive plays in the these women's lives.<sup>18,19,20</sup> Given that most women are diagnosed with HIV during their reproductive years, a positive HIV diagnosis has extensive ramifications for self-perceptions of life and the wellbeing of a woman's existing and future children (should she wish to have them). HIV-positive women have the double burden of confronting threats to their own health and deciding what is best for their children, and both of these considerations are framed by the medical discourse of HIV. A positive HIV diagnosis also poses dilemmas for the women's clinicians in managing the best interests of women and infants.

HIV-positive women have the double burden of confronting threats to their own health and deciding what is best for their children, and both of these considerations are framed by the medical discourse of HIV.



Karalyn McDonald's research found that despite a positive diagnosis being an overwhelming and devastating experience, the identity of motherhood was able to be sustained for most women.<sup>21</sup> For women who were not yet mothers, although a positive diagnosis could initially shatter dreams of motherhood, it could also reinforce the idea of motherhood as an integral part of their future. An HIV-positive diagnosis for women who were already mothers was usually accompanied by a great deal of anxiety, pain and loss; women diagnosed during pregnancy not only had to grapple with the magnitude of this news, but also make important and life-altering decisions about their pregnancy.

Ultimately, most of the women who were not mothers when they were diagnosed were able to plan for a future that included children. For many, time played a crucial role in this process, as they revised their imagined life trajectory from one of imminent death to a life that could include children and hope for the future. Minimising the focus on HIV was important to many of these women as they described having children and becoming a mother, as representations of a 'normal' life. Factors that influenced the women to pursue or consider motherhood after the PACTG 076 protocol (a treatment regimen to reduce the risk of mother-to-child transmission [MTCT])<sup>22</sup> usually included clinical markers (used to determine the disease progression of HIV within an individual), antiretroviral treatments and other medical intervention in the prevention of MTCT transmission. More than 10 years on, information about having children and women's reproductive health remains an important feature of service provision for HIV-positive women.

### **Attitude towards treatment**

Earlier in the epidemic, it was noted that women were generally more sceptical than men about the benefits of antiretroviral treatments. Futures survey data from 1997 and 1999 found

that women were less likely than men to be using antiretroviral treatment and less likely to believe that antiretroviral treatments meant better prospects for people living with HIV. However, by 2009, over three-quarters of women living with HIV (77.7%) were taking antiretroviral treatment and a greater proportion believed that treatments meant better prospects for HIV-positive people, even though women remained more likely than men to believe that combination antiretroviral drugs are harmful.<sup>23</sup> In part, it is likely that these women's attitudes were influenced by the lack of support from a large 'HIV community' that is often a support mechanism experienced by gay HIV-positive men.<sup>24</sup> In the past there has also been a dearth of information available about treatments and side-effects that are specific to the female body.

### **Service use**

Women living with HIV demonstrate a different pattern of service use to gay/bisexual men living with HIV.<sup>25</sup> Women are more likely to see an HIV-specialist for their HIV treatment and a non-HIV general practitioner for their general medical treatment; in contrast, gay/bisexual men living with HIV are more likely to see an HIV s100 general practitioner for their HIV treatment and general medical treatment.<sup>26</sup> The differences in service use can be partly explained by the differences in the areas where women and gay/bisexual men living with HIV reside; however, it also appears to reflect a difference in service preferences and suitability.<sup>27,28</sup>

An HIV-positive diagnosis for women who were already mothers was usually accompanied by a great deal of anxiety, pain and loss; women diagnosed during pregnancy not only had to grapple with the magnitude of this news, but also make important and life-altering decisions about their pregnancy.

### **Experience of discrimination and unwanted disclosure**

Women remain more likely than men to report unwanted disclosure of their HIV status and the experience of health service discrimination.<sup>29</sup> In 2009, 73.6% of women living with HIV reported unwanted disclosure of their HIV status at some point; for 31.2% overall, this unwanted disclosure occurred in the last two years.<sup>30</sup> Similarly, 47.1% of women living with HIV reported experiencing less favourable treatment at health services, with just over half of these women (25.7% overall) experiencing such discrimination in the last two years.<sup>31</sup> Health workers have been reported to play a role in both the experience of unwanted disclosure and health service discrimination.<sup>32</sup> A number of factors have been postulated as explanations to the greater proportion of women who experience health service discrimination. These include greater contact with mainstream services, greater need to access health services, women's biological and social role as mothers, women's social status and injecting drug use practices.<sup>33</sup>

*continued overleaf*

## Looking forward: what still needs to be addressed?

The availability of effective treatments to prevent mother-to-child transmission and access to reproductive technologies for people living with HIV has allowed a number of women living with HIV to fulfil their dreams of motherhood. However, HIV-positive women are more burdened by unwanted disclosure and health service discrimination than HIV-positive men, and also experience immense financial difficulties. Factors leading to increased stigma and discrimination and unwanted disclosure for women living with HIV need to be addressed, as does the financial situation of women living with HIV. The *HIV Futures 7* study, currently underway, will provide up-to-date information to inform future efforts to address factors such as these. Gender differences in the experience of living with HIV need to remain on the agenda, particularly in relation to current issues such as ageing with HIV.

**We encourage women living with HIV to complete the survey, available at [www.hivfutures.org.au](http://www.hivfutures.org.au). A hardcopy can be obtained through HIV organisations or by calling 1800 064 398.**

... HIV-positive women are more burdened by unwanted disclosure and health service discrimination than HIV-positive men, and also experience immense financial difficulties. Factors leading to increased stigma and discrimination and unwanted disclosure for women living with HIV need to be addressed, as does the financial situation of women living with HIV.

## References

- 1 The Kirby Institute. (2011). *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2011*. 2011, The Kirby Institute, the University of New South Wales, Sydney.
- 2 McDonald, K., Kirkman, M. (2011). HIV-positive women in Australia explain their use and non-use of antiretroviral therapy in preventing mother-to-child transmission. *AIDS Care*, 23(5), 578–584.
- 3 Koelmeyer, R., et al. (2010). *HIV Futures 6: Making Positive Women's Lives Count*, in Monograph Series Number 77. The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.
- 4 Thorpe, R., McDonald, K., Grierson, J. (2007). *HIV Futures 5: Life as women know it*, in Monograph Series Number 63. The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.
- 5 McDonald, K., Thorpe, R., Grierson, J. (2005). *The Journey Continues: Women living with HIV/AIDS in Australia*, in Monograph Series Number 51. The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.
- 6 McDonald, K., Misson, S., Grierson, J. (2002). *Juggling with HIV: The intricacies of positive women's lives in Australia today*, in Monograph Series Number 38. The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.
- 7 McDonald, K., et al. (2000). *A complex uncertainty: Women on health, hope and living with HIV in Australia*, in Monograph Series Number 19. The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.
- 8 McDonald, K., et al. (1998). *Standing on shifting sand: Women living with HIV/AIDS in Australia*. National Centre in HIV Social Research, La Trobe University, Melbourne.
- 9 McDonald, K. (2006). *Common Threads: Women's stories of pregnancy, parenting and living with HIV*. Australian Research Centre in Sex, Health and Society, La Trobe University and Positive Women Victoria, Melbourne.
- 10 McDonald, K. (2008). *"What about motherhood?": Women's journeys through HIV and AIDS*, in unpublished PhD thesis. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.
- 11 Koelmeyer, R., et al., op. cit.
- 12 *ibid.*
- 13 The Kirby Institute, op. cit.
- 14 Koelmeyer, R., et al., op. cit.
- 15 *ibid.*
- 16 The Kirby Institute, op. cit.
- 17 *ibid.*
- 18 Koelmeyer, R., et al., op. cit.
- 19 McDonald, K., Misson, S., op. cit.
- 20 McDonald, K., et al. (2000). op. cit.
- 21 McDonald, K., (2008). op. cit.
- 22 Perinatal HIV Guidelines Working Group. (2006). *Public Health Service Task Force Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1 Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV-1 Transmission in the United States*. National Institute of Health, Bethesda, MD.
- 23 Koelmeyer, R., et al., op. cit.
- 24 McDonald, K., Bartos, M., Rosenthal, D. (2001). Australian women living with HIV/AIDS are more sceptical than men about antiretroviral treatment. *AIDS Care*, 13(1), 15–26.
- 25 Koelmeyer, R., et al., op. cit.
- 26 *ibid.*
- 27 *ibid.*
- 28 Thorpe, R., Grierson, J., Pitts, M. (2008). Gender differences in patterns of HIV service use in a national sample of HIV-positive Australians. *AIDS Care*, 20(5), 547–52.
- 29 Koelmeyer, R., et al., op. cit.
- 30 *ibid.*
- 31 *ibid.*
- 32 Thorpe, op. cit.
- 33 *ibid.*

**Rachel Koelmeyer is Research Officer, Living with HIV Program Research Team at the Australian Research Centre in Sex, Health & Society, La Trobe University. Dr Karalyn McDonald is a Research Fellow with the Infectious Diseases Unit, Monash University. Dr Jeffrey Grierson is Senior Research Fellow at the Australian Research Centre in Sex, Health & Society, La Trobe University**

# WOMEN AND HIV: 30 YEARS ON. WHERE TO FROM HERE?

By Jane Costello

**'This epidemic unfortunately remains an epidemic of women.'**

— Michel Sidibé, Executive Director of UNAIDS<sup>1</sup>

In an article published last year to commemorate the 30th anniversary of the HIV/AIDS epidemic, Serra Sippel, an American women's rights activist and President of the Center for Health and Gender Equity (CHANGE), had this to say on the global response to the anniversary as regards women:

*'In the subsequent days, we've seen stories measuring progress, touting the newest prevention methods, and updating the statistics. However, in all the talk, there has been one core aspect of HIV/AIDS that has been absent: that women comprise 50 percent of those living with HIV globally, 60 percent of those infected in sub-Saharan Africa and that 72 percent of all young people living with HIV/AIDS in southern Africa are girls between the ages of 15 and 24.'*<sup>2</sup>

Despite Michel Sidibé lamentation that 'HIV remains an epidemic of women', one might be forgiven for thinking that Sippel's is a lone voice in the wilderness seeking policy responses that address the female epidemic. However, Sippel is in fact one of many female activists growing increasingly angry about the disconnect between what is being said in official communiqués, and the mobilisation of resources by organisations such as the United Nations to address the situation.

Globally, over half of the people living with HIV are now women.<sup>3</sup> HIV is now a leading cause of death and disease for women in their reproductive years (ages 15–44), as well as for adult women aged between 20–59; one in five deaths

among women aged 20–59 is linked to unprotected sex.<sup>4</sup> An increasing number of female HIV activists are questioning government and non-government organisations' meaningful commitment to the cause of women and HIV.

## Fighting to be heard

Silvia Petretti, an HIV-positive activist who works for Positively UK, travelled to New York as a delegate representing the Global Network of People Living with HIV (GNP+) at the UN High Level Meeting on AIDS (HLM) in June 2011; the HLM was held to coincide with the 30th anniversary of HIV. Petretti's disillusionment with the political declaration produced from this meeting was more than evident, despite her enthusiasm and initial high hopes for the outcomes. As she explains:

*'... I profoundly believe that our meaningful involvement can make this response much more effective. However, during the HLM I started having serious doubts that an institution with so little female representation could devise a political declaration meaningful to women – nearly 52% of the 34 million people who live with HIV worldwide. During the General Assembly, I watched one male government minister or high-level official after the other making solemn declarations on their commitment to HIV; often they came from countries where I knew women and other affected populations get very little legal or political protection. One of the lowest moments was the panel session on Women and Girls, where four out of five panellists were men. I was wondering whether they would ever*

*have a session on men who have sex with men, mostly run by women?'*<sup>5</sup>

In hoping to make a meaningful contribution, Petretti and her organisation helped coordinate and participated in a global consultation on women's wishes regarding HIV. This consultation produced five strategic goals on which Peretti commented:

*'... women's demands were not surprising or unreasonable. What seems really shocking is that, firstly, our claims are still not being addressed, and secondly, that in 30 years of AIDS, this was the first global consultation among women supported by UNAIDS and carried out by a partnership of NGOs.'*<sup>6</sup>

Peretti went on to note that while the political declaration that came out of this meeting was forward-thinking and progressive, it again failed to adequately address women's issues. She pointed out that despite the disproportionate number of women affected by the epidemic, there were 'only four paragraphs dedicated to women, with the only numeric targets relating to mother-to-child transmission and maternal health: women are only important as "baby makers". Our health and prevention needs at all stages of our lives are ignored.'<sup>7</sup>

A coalition of positive women's networks from around the world signed up to an international policy brief setting out common challenges faced by positive women's networks around the world. The brief was originally launched at the 55th Commission on the Status of Women in February 2011 to commemorate the 100th anniversary year of International Women's Day and the 30th anniversary year of HIV, and later relaunched at the International Women's Summit in Zurich and the International AIDS Conference in Rome. Entitled *Put Your Money Where Your Mouth Is: Invest in Women and Girls Living with HIV, 2011 Time for Change!*<sup>8</sup>,

*continued overleaf*

the document outlines the challenges faced by positive women's networks and offers four broad recommendations for change. The grievances articulated by many signatories to the document again question the commitment of international non-governmental organisations' to the cause of women and HIV:

*'Why do we have still to fight for our voices to be heard in places where decisions that so deeply affected our lives are being made? Why is it that so many international organisations that claim to prioritise the rights and needs of women and girls living with HIV and proclaim their commitment to our meaningful involvement in decisions which affect our lives, still systematically exclude us? ... In this policy briefing paper, as we enter the fourth decade of this pandemic, we address these questions to all the world's leading scientists, clinicians, public health experts, as well as to all the UN Family, the Global Coalition on Women and AIDS (GCWA), the Global Fund, PEPFAR, the World Bank-MAP project, the IMF, governments, private foundations, not-for-profit organisations and all others who seek to contribute to an effective response to the HIV pandemic.'*<sup>9</sup>

Comments such as these clearly show that on the 30th anniversary of HIV, many women feel excluded from meaningful involvement and consultation around global programs for people living with HIV operated by the likes of the United Nations, despite its declared commitment to tackle gender inequality.

While the majority of women living with HIV currently reside in the developing countries of sub-Saharan Africa, the World Health Organization and UNAIDS have flagged that, in other parts of the world, the proportion of women living with HIV has been increasing over the last decade.

## HIV and women – global patterns are changing

While the majority of women living with HIV currently reside in the developing countries of sub-Saharan Africa, the World Health Organization and UNAIDS have flagged that, in other parts of the world, the proportion of women living with HIV has been increasing over the last decade.<sup>10</sup> This increase includes 'married or regular partners of clients of sex workers, the partners of IDU (injecting drug users), and MSM (men who have sex with men) and clients of sex workers, as well as female sex workers and injecting drug users'.<sup>11</sup> This suggests that in regions where women have not traditionally been considered part of 'at risk' populations – namely men who have sex with men, sex workers and injecting drug users – the demographics of the epidemic may be changing. This has major implications for public health policy and service delivery in many developed countries, and suggests a potential epidemic amongst the heterosexual community. 'Generally women are at a greater risk of heterosexual transmission of HIV. Biologically women are twice more likely to become infected with HIV through unprotected heterosexual intercourse than men.'<sup>12</sup>

In the United Kingdom (UK), the majority of cases of HIV transmissions have been acquired through heterosexual sex, with the incidence of transmission occurring overseas and diagnosis taking place after arrival in the UK.<sup>13</sup> However, the proportion of cases of HIV acquired overseas appears to be diminishing; the Health Protection Agency reports that 'the

number of new HIV diagnoses among people infected overseas has decreased since 2004, whilst diagnoses among people who most likely were infected heterosexually within the UK have recently risen dramatically, from 320 in 2001 to 1,090 in 2010. By 2010, people who were infected within the UK accounted for a third of all heterosexuals newly diagnosed that year.'<sup>14</sup> Approximately 24 to 27% of people living with HIV in the UK are unaware of their infection.<sup>15</sup>

In the United States (US), data from 2008 indicated that 28% of people living with HIV were heterosexual; in 2009 27% of new HIV infections were attributed to heterosexual contact.<sup>16</sup>

The mode of transmission of HIV among women in the US is mainly attributed to heterosexual contact or injecting drug use. Women account for around a quarter of new cases of HIV, with '23% of estimated new HIV infections in 2009 and 25% of those living with HIV infection in 2008.'<sup>17</sup> The rates of HIV infection among women are disproportionately high in the African-American and Latina populations:

*'Even though African-American women and Latinas ages 13–24 account for only 32 percent of the U.S. female youth population, they account for roughly 83 percent of new HIV infections among young females in the US. In addition, black women account for 62 percent and Latinas for 19 percent of cumulative AIDS cases among women 13 to 24. Numerous studies have found that the major mode of transmission in this population is heterosexual contact.'*<sup>18</sup>

Despite these numbers, Serra Sippel highlights that the 'US National HIV/AIDS Strategy issued in July 2010 has no gender strategy. In fact, women barely appear in the US National HIV/AIDS Strategy and its implementation plan.'<sup>19</sup>

## HIV and STIs in Australia

In Australia, where transmission occurs primarily through men, women



living with HIV are regarded as a minority within a minority, making up 13.9% of those newly diagnosed in 2010. Sixty-seven percent of people newly diagnosed with HIV in 2010 were among men who have sex with men; 27.7% were exposed through heterosexual contact; 2.4% were due to injecting drug use; and a further 2.3% were men with a history of both injecting drug use and sex with other men.<sup>20</sup> However, given the progression of the epidemic amongst the heterosexual population in other developed countries – and among women in particular – Australia should not be too complacent in this respect.

In the US, health professionals are aware of the missed opportunity in not having an integrated HIV and STI (sexually transmissible infection) testing and health service, but have noted anecdotally that where there is a high prevalence of HIV, there is also a high prevalence of STIs.<sup>21</sup>

Whilst there is a relatively established culture of HIV testing within the gay community<sup>22</sup> this is not the case in the heterosexual community. The reluctance to test among heterosexuals would appear to be borne out by anecdotal data in the US, where heterosexuals and particularly young women are not perceived to be in an 'at risk' group. According to Jennifer Irwin, Deputy Executive Director at Health and Education Alternatives for Teens (HEAT), the problem lies in the fact that 'A lot of [young women] still tell themselves "I'm not a young, gay male. I'm having heterosexual sex, therefore I really don't need to get tested."<sup>23</sup>

Similarly, results from a 2009 Australian survey conducted for the Department of Health and Ageing found that only 52% of survey respondents aged 15–29 said they had used a condom last time they had sex, with over 60% admitting they had never been screened for STIs. When asked to assess their own likelihood of catching an STI, the majority perceived themselves as 'unlikely' to do so.<sup>24</sup> With this in mind, it is not much of a leap

of faith to make a correlation between the current increase in STIs and a possible increase HIV in the future, although there is currently no evidence to substantiate this.

'A dangerous complacency has affected the broader community – a quiet sense that if you are not gay, an injecting drug user or a sex worker, HIV is not a risk for you,' says Australasian Society of HIV Medicine CEO Levinia Crooks. 'Our youth barely understand what HIV is. Yet STIs amongst this group are soaring. If their attitude to unsafe sex continues, it will only be a matter of time before HIV infections increase too.'<sup>25</sup>

So as women living with HIV – where do we go to from here in terms of the epidemic ... ? As the UK activist Silvia Peretti concludes, 'there is still much work to do. I am still convinced that unless those of us directly affected by HIV are meaningfully involved, the epidemic will not recede.'<sup>26</sup>

## References

- 1 UN News Centre. (2010, 9 June). Noting progress to date, Ban urges greater efforts against HIV/AIDS. Retrieved from: <http://www.un.org/apps/news/story.asp?NewsID=34977&Cr=aids&Cr1>
- 2 Sippel, S. (2011, 13 June). 30 Years is Enough: An HIV Strategy for Women Now. *Huffington Post*. Retrieved from: [http://www.huffingtonpost.com/serra-sippel/hiv-aids-women\\_b\\_875569.html](http://www.huffingtonpost.com/serra-sippel/hiv-aids-women_b_875569.html)
- 3 World Health Organization (WHO) and UNAIDS. (2008). *Gender Inequalities and HIV*. Retrieved from: [http://www.who.int/gender/hiv\\_aids/en/](http://www.who.int/gender/hiv_aids/en/)
- 4 WHO. (2009). *Women's Health*, Fact sheet No. 334, November, 2009. Retrieved from: <http://www.who.int/mediacentre/factsheets/fs334/en/index.html>
- 5 Peretti, S. (2011, 17 July). There is Still Much Work to Do. Retrieved from: <http://www.aidsmap.com/There-is-still-much-work-to-do/page/2020144/>
- 6 *ibid.*
- 7 *ibid.*
- 8 Various Signatories (2011). *Put Your Money Where Your Mouth Is: Invest in Women and Girls Living with HIV, 2011 Time for Change!* Retrieved from: [http://www.womeneurope.net/index.php/page/Policy\\_Brief\\_2011/en](http://www.womeneurope.net/index.php/page/Policy_Brief_2011/en)
- 9 *ibid.*
- 10 WHO and UNAIDS 2008, op. cit.
- 11 *ibid.*
- 12 UNAIDS (2009, 15 July). *A Strategic Approach: HIV & AIDS and Education*. Retrieved from: <http://www.unaids.org/en/Resources/PressCentre/>

- Featurestories/2009/June/20090615UNESCO/
- 13 Health Protection Agency (2011). *HIV in the United Kingdom: 2011 report*. Health Protection Services, Colindale, London. Retrieved from: <http://www.hpa.org.uk/Publications/InfectiousDiseases/HIVandSTIs/1111HIVintheUK2011report/>
  - 14 *ibid.*
  - 15 *ibid.*; BBC News Health (2010, 26 November). A Quarter of Those with HIV 'Unaware They Have Virus'. Retrieved from: <http://www.bbc.co.uk/news/health-11838218>; Taylor, J. (2010, 21 August). HIV is no Longer an Epidemic, But The Stigma Is, *The Independent*. Retrieved from: <http://www.independent.co.uk/life-style/health-and-families/health-news/hiv-is-no-longer-an-epidemic-but-the-stigma-is-2058059.html>
  - 16 Department of Health and Human Services, Centers for Disease Control and Prevention (CDC). (2010). *HIV in the United States*. CDC Fact sheet. Retrieved from: <http://www.cdc.gov/hiv/resources/factsheets/us.htm>
  - 17 *ibid.*
  - 18 Terrell, K. (2011, 25 January). The Rising HIV Rates Among Young Women and Girls of Color: What's Going On? Retrieved from: <http://www.thebody.com/content/art60252.html?getPage=1>
  - 19 Sippel, S., op. cit.
  - 20 The Kirby Institute. *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2011*. The Kirby Institute, The University of New South Wales, Sydney.
  - 21 Terrell, K., op. cit.
  - 22 O'Donnell, D. (2011). NSW HIV Rates Remain Stable. NSW Government Health media release, 31 August. Retrieved from: [http://www.health.nsw.gov.au/news/2011/20110831\\_00.html](http://www.health.nsw.gov.au/news/2011/20110831_00.html)
  - 23 Terrell, K., op. cit.
  - 24 Australian Society of HIV Medicine (ASHM). (2010). ASHM Media release: Australian youth at risk of HIV, 1 December. Retrieved from: [http://www.ashm.org.au/images/Media\\_Releases/WAD\\_media\\_release\\_20101130.pdf](http://www.ashm.org.au/images/Media_Releases/WAD_media_release_20101130.pdf)
  - 25 *ibid.*
  - 26 Peretti, S., op. cit.

**Jane Costello is passionate about empowering and improving the lives of people living with HIV. She is currently Vice President of Positive Life NSW, and a member of both the NAPWA Women's Network and the Heterosexual HIV/AIDS Service NSW (HHAS) reference group. Jane has been involved in the HIV sector for a number of years as a facilitator, speaker, presenter and researcher. She holds a Masters in International Studies (MINTS) and is currently completing a PhD doctoral thesis.**

# 'YOU DON'T GROW ANOTHER HEAD': THE EXPERIENCE OF STIGMA AMONG HIV-POSITIVE WOMEN IN AUSTRALIA

By Karalyn McDonald

## HIV/AIDS and stigma

The prevalence of HIV/AIDS-related stigma and discrimination has been widely documented.<sup>1-4</sup> Even before HIV was identified, there was societal stigmatisation of certain groups of people such as homosexuals, sex workers, injecting drug users, and those with cultural and linguistic differences. The emergence of this disease has only served to heighten the stigmatisation of these minority groups.<sup>5</sup> Women who are HIV-positive are often assumed to be sex workers or injecting drug users and their stigmatisation is compounded if they are from ethnic minority groups<sup>6</sup> or do have a history of sex work or drug use<sup>7,8</sup>. Reidpath and Chan<sup>9</sup> referred to this as 'layers' of stigma. Not only do these women have a feared, contagious disease, but they also are assumed to have deviance in their personal traits.

HIV-positive women encounter additional stigma because of their childbearing capabilities<sup>10,11</sup> as well as their roles as mothers; women who express their desire to pursue pregnancy are sometimes accused of being selfish, inconsiderate, uncaring, and even immoral<sup>12,13</sup>. Stigma has been found to be 'virtually synonymous with the experience of HIV infection in women.'<sup>14</sup>

## Methodology

The analysis presented in this article formed part of my doctoral thesis examining the impact of an HIV diagnosis on women's thoughts and feelings about motherhood; including experiences of stigma, discrimination and disclosure. My research involved interviews with 34 HIV-positive women from around Australia who

HIV-positive women encounter additional stigma because of their childbearing capabilities as well as their roles as mothers; women who express their desire to pursue pregnancy are sometimes accused of being selfish, inconsiderate, uncaring, and even immoral

had been diagnosed during their childbearing years. The interviews were conducted in 2001.

Intermittent contact was made with these women during the following six years. This enabled participants to update information and validate interpretations of their accounts. The resource book, *Common Threads: Women stories of pregnancy, parenting and living with HIV*<sup>15</sup>, was developed in consultation with the participants and the support organisation, Positive Women Victoria Inc.

La Trobe University Human Research Ethics Committee approved the research. Participants' confidentiality is protected by the use of pseudonyms and the concealment of identifying details in reporting results. Information about counselling and referral services was offered to each participant.

## Results

Of the 34 women, 28 women were mothers to 51 children in total. Sixteen women had given birth to 23 children in total since their diagnosis. All but two of these children were born after 1994, following the introduction of the Pediatric AIDS Clinical Trials Group (PACTG) 076 protocol (which significantly reduced the likelihood of mother-to-child transmission). Only one child, born in 1994, was HIV-positive. Two women were pregnant with their first child at the initial interview and updated details about their birthing and mothering experiences in postnatal interviews. Four women had been diagnosed during a pregnancy; all proceeded to term.

## Stigma in the context of motherhood

Almost half of the women in my study told of encountering healthcare professionals who openly opposed or advised against their desires to pursue pregnancy.<sup>16</sup> However, most of the women who had their babies after the 076 protocol were able to find a supportive doctor to care for them

during their pregnancy and birth. Similarly, most women concluded that the majority of the healthcare professionals they dealt with in the hospital were very considerate of their confidentiality. Particularly notable were the stories from women who had given birth to two children since they were diagnosed, and the differences they reported between the two experiences. Some women even received apologies from staff who remembered how the women were treated and how much procedures had changed to try to ensure that women did not feel stigmatised.

Stigma in this context was often experienced by women, who said that they had to 'educate' nursing staff in an attempt to prevent them from 'making assumptions about who I was and what my life was like.' When Janice was in hospital after the birth of her daughter, she said the midwives asked her a lot of questions, such as, 'Are you sure she's going to be all right? How did you get it? And how long do you think you're going live for?' While Janice interpreted their questions as curiosity, she was 'bothered' because she felt they should have known the answers to the questions they were asking.

However, friends and family also sometimes objected to women's desires to become mothers because of their HIV status. Isabelle recalled that when she was considering motherhood at one stage, she spoke to her brother who is a doctor, about her thoughts of motherhood and his response was that 'It would be irresponsible. What if the child is positive?'

Miranda interpreted her decision to terminate her first (wanted) pregnancy as a result of the lack of support she received from family and friends, who said things to her such as, 'How could you? You won't be around to bring the child up. What if the child's sick?' Miranda then constructed an account of her next two pregnancies that she believed her friends and family would find more acceptable: telling them they were both accidents', explaining:

*'People accept it better if you say, "Oh, I accidentally fell pregnant and now I'm going through with it," rather than saying, "Oh, this is my situation and I want a child," because they consider that selfish. ... When I was pregnant with Jack, people, even family, were a bit like, "Oh, how could you do it again? You should just be happy that you have one child that is well. How could you go through the whole thing again?" It's like they think it's a bit greedy. So again I said it was an accident. There is this sense of shame. I felt guilty and ashamed when I was pregnant, like I couldn't really enjoy it because pregnancy is supposed to be this real spiritual thing, but I felt embarrassed when I was pregnant.'*

As Isabelle and Miranda made clear, stigma is often enacted by the very people from whom many women expect support and understanding. Such unsupportive and even antagonistic responses result in most women becoming very selective about to whom they told their accounts, and what they actually told them.

### Managing stigma

The women worked to manage stigma, which included minimising harm to their children and passing as a 'normal mother'.<sup>17</sup> In the early years of her diagnosis, Denise worked very hard at passing as a 'normal' woman to the outside world in the hope that it would protect not only the secret of her HIV status but also that of her drug use:

*'I was always working part-time in child care and studying and running the house because I always thought*

*if I, like, kept my house really clean and spotless and was on every parent committee that existed, no one would ever know that my family, my partner and I, used heroin.'*

Also implicit in the discussion of stigma is disclosure. Stigma affects women's decisions about disclosure to their family and friends, including their children.<sup>18</sup> Women told of spending considerable energy managing the risk for enacted stigma; including trying to prevent unwanted disclosure.

Around one in four women had experienced unwanted disclosure. This was either in the form of people they had told telling others; healthcare professionals being indiscreet; or well-meaning family members insisting on another family member being told even when it was not what the woman herself wanted. A few women felt they were pressured into disclosing to a parent by another family member who 'thought they had a right to know.' The consequence to this disclosure was often a very anxious parent who required a great deal of support from his or her daughter. This was often difficult because she was either still grappling with her diagnosis or perhaps lived too far away to provide effective support and reassurance.

Unwanted disclosure caused additional angst when it directly affected participants' children. Lily was forced to leave the town in which she and her

*continued overleaf*

Stigma in this context was often experienced by women saying that felt they had to 'educate' nursing staff in an attempt to prevent them from 'making assumptions about who I was and what my life was like.'

son were living when an ex-lover told a lot of people, including her neighbours, that she and her son were HIV-positive:

*'The discrimination and the abuse we received meant that we were just ostracised from everybody. Nobody talked to us anymore. Zach lost all his playmates and it was just him and me existing, and when we were out we were stared at and talked about and people called out names and abuse.'*

Unwanted disclosure could also inadvertently come from one's children. To prevent ensuing discrimination, many women gave considerable thought to when their child would be able to understand the gravity of the information in relation to how others might react to this news. Denise had disclosed her status to her son, but she and her partner were yet to tell their younger daughter. Part of the decision to keep the information from her was the fear that, when she was younger, 'she would have gone to school and told the whole assembly.'

Even adult children did not always understand the risk of disclosure and how their mother expected them to refrain from telling others. Audrey's son told one of his friends about his mother's HIV status without her permission and when this friend revealed that she knew, Audrey was surprised and upset. She told her son

'that he didn't have the privilege of telling people my health status; that it was up to me.' Her son did not understand her reaction because this friend did not treat her any differently. However, Audrey explained that she felt it was her right to decide who knew and that knowing who knew about her status influenced the kind of conversations she might have.

Having others know about their status without their permission or knowledge compromised women's attempts at passing as 'normal' and removed their sense of control of managing information about themselves and potential stigma. However, disclosure to a loved one can be burdensome for the person receiving the news and a few women recognised that unwanted disclosure could be avoided by encouraging loved one or friends to confide in one another rather than tell an additional person.<sup>19</sup> Laura told the people she disclosed to the names of other people who knew and told them to talk to each other:

*'When you give that sort of information to someone they have to do something with it because it is really overwhelming. ... They're going to talk about it to someone, so you need to give them options of people that it doesn't matter if they talk to them and that's what I tried to do.'*

## Stigma, peer support and isolation

Among the women I spoke with, there was a contrast between those women who felt part of a group and for whom meeting other HIV-positive women helped to reduce their feelings of stigma, and those women for whom mixing with other HIV-positive women increased or heightened their sense of stigma. This was somewhat dependent on whether the woman was diagnosed before or after the availability of antiretroviral treatments and the length of time since diagnosis. Almost all of the women had met with another HIV-positive woman at some stage since their diagnosis. These women had appreciated meeting with other women; for some, it played a vital part in the acceptance of their disease and reduced their sense of isolation. For many, it provided hope for longevity and continuity of the life they had envisaged before their diagnosis. Audrey remembered her first meeting of 'women who have survived 20 years' and described it as 'awesome; it was just incredible.'

It was very important for some women to meet with another HIV-positive woman soon after they were diagnosed. For others, the desire to do so could take years to emerge. Brooke did not meet with other women until four years after her diagnosis because 'I wasn't ready.' But once she did, she found that 'it all started to get better – just listening to the experiences of other women.' Adele also resisted meeting with other positive women 'because I was just coping, struggling to cope with it.' Although Adele did have an HIV-positive gay male friend 'who understood what I was going through', she still had not yet met with another HIV-positive woman, saying, 'I don't feel like there is anything missing from my life. I mean they might help but I certainly don't feel that I need it now.'

... there was a contrast between those women who felt part of a group and for whom meeting other HIV-positive women helped to reduce their feelings of stigma, and those women for whom mixing with other HIV-positive women increased or heightened their sense of stigma.



A couple of women in my study avoided other HIV-positive people because they believed it would confirm or reinforce their status. Clare had met a few other HIV-positive people but she did not disclose her status to them. She interpreted her reluctance to disclose as her own discomfort with her status, saying she was in the 'early stage of "I'm not 100% comfortable with everything yet"'. She feared that she might 'freak out' and that it would reinforce her status: 'Well, I really am and everyone knows I am now.'

## Conclusion

HIV is largely absent from mainstream Australian society. Women make up less than 10% of all HIV-positive people in Australia<sup>20</sup> and they are widely dispersed geographically. Early in the epidemic, women were identified as guilty (sex workers, injecting drugs users or promiscuous women) or innocent (infected from blood products or husbands). HIV-positive women's support organisations have worked hard to eliminate this additional marginality in an effort to support all women. However, women's childbearing capabilities make women vulnerable to stigma, as vectors of disease, posing a threat to potentially 'innocent' children. It was within this context that many women in this study experienced stigma.

More than two decades after the emergence of this disease, stigma remains a barrier to HIV-positive women in Australia having access to complete care and support. These women's accounts of stigma highlight the need for continued education among healthcare professionals and the wider public, as well as for targeted programs for HIV-positive women and their families to address the experiences of perceived and enacted stigma and the subsequent isolation experienced by many women living with HIV.

## References

- 1 Scambler, G. (2009). Health-related stigma. *Sociology of Health & Illness*, 31(3), 441–55.
- 2 Herek, G. (1999). AIDS and stigma. *American Behavioral Scientist*, 42, 1102–12.
- 3 Alonzo, A., Reynolds, N. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science & Medicine*, 41(3), 303–15.
- 4 Sontag, S. (1989). *AIDS and Its Metaphor*. The Penguin Press, New York.
- 5 Malcolm, A., Aggleton, P., Bronfman, M., et al. (1998). HIV-related stigmatization and discrimination: its forms and contexts. *Critical Public Health*, 8(4), 347–70.
- 6 Lekas, H., Siegel, K., Schrimshaw, E. (2006). Continuities and Discontinuities in the Experiences of Felt and Enacted Stigma Among Women With HIV/AIDS. *Qualitative Health Research*, 16(9), 1165–90.
- 7 Berger, M. (2004). *Workable Sisterhood: The Political Journey of Stigmatized Women with HIV/AIDS*. Princeton University Press, Princeton.
- 8 Barnes, D., Alforque, A., Carter, K. (2000). 'Like I just got a death sentence': Conditions affecting women's reactions to being told their HIV antibody test results and the impact on access to care. *Research in the Sociology of Health Care*, 18, 3–33.
- 9 Reidpath, D., Chan, K. (2005). Method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*, 17(4), 425–32.
- 10 Lekas, op. cit.
- 11 Gurevich, M., Mathieson, C., Bower, J., Dhayanandhan, B. (2007). Disciplining bodies, desires and subjectivities: Sexuality and HIV-positive women. *Feminism & Psychology*, 17(1), 9–38.
- 12 McDonald, K. (2002). I was devastated to think I couldn't have a child: The role of motherhood in the lives of HIV-positive women in Australia. *The Fertile Imagination: Narratives of Reproduction (special issue)*, 18 (2):123–41.
- 13 McDonald, K. (2006a). The best experience of my life: HIV positive women on pregnancy and birth in Australia. In: Tankard Reist, M. (ed). *Defiant Birth: Women Who Resist Medical Eugenics*. Spinifex Press, North Melbourne, 144–58.
- 14 Sandelowski, M., Lambe, C., Barroso, J. (2004). Stigma in HIV-positive women. *Journal of Nursing Scholarship*, 36(2), 124.
- 15 McDonald, K. (2006b). *Common Threads: Women's stories of pregnancy, parenting and living with HIV*. Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University and Positive Women Victoria.
- 16 McDonald, K. (2006a), op. cit.
- 17 Goffman, E. (1963). *Stigma: Notes on the Management of a Spoiled Identity*. Penguin, Harmondsworth.
- 18 McDonald, K. (In Press). Do You Tell Your Kids? What Do You Tell Your Kids? When Do You Tell Your Kids? How Do You Tell Your Kids?: HIV-Positive Mothers, Disclosure and Stigma. In: Liamputtong, P. (ed), *Women, Motherhood and Living with HIV/AIDS: A Cross-Cultural Perspective*, Springer.
- 19 Persson, A., Richards, W. (2008). From closet to heterotopia: a conceptual exploration of disclosure and 'passing' among heterosexuals living with HIV. *Culture, Health and Sexuality*, 10(1), 73–86.
- 20 National Centre in HIV Epidemiology and Clinical Research (NCHECR). (2010). *Australian HIV Surveillance Report, (Vol 26, No 4)*. NCHECR, Sydney.

**Karalyn McDonald is a Research Fellow at Monash University in the Infectious Diseases Unit. The research presented in this article was conducted while she was a PhD candidate at the Australian Research Centre in Sex, Health and Society, La Trobe University.**

HIV-positive women's support organisations have worked hard to eliminate this additional marginality in an effort to support all women. However, women's childbearing capabilities make women vulnerable to stigma, as vectors of disease, posing a threat to potentially 'innocent' children.

# EXPERIENCES OF WOMEN FROM CULTURALLY AND LINGUISTICALLY DIVERSE BACKGROUNDS LIVING WITH HIV: CHILDREN AND PARENTING

By Henrike Körner

**‘But us women, we fight hard to be strong. We, I don’t know how to put it, but us women we make sure that we are strong.’** (Margaret)

This article draws on a small subsample of seven heterosexual women from culturally and linguistically backgrounds who participated in a larger study on the intersections between migration, gender and sexual orientation for people living with HIV in Sydney. One of the topics explored through in-depth interviews was children and parenting. All women in this subsample had children. The number of children ranged from one to six, and the children’s ages ranged from 3 to 31. Out of the seven women, two were married and five were sole parents.

## Staying alive

The women’s initial reactions to being diagnosed HIV-positive centred on the

need to stay alive and stay strong for the sake of their children. The women described how the need to care for their children gave them the motivation to carry on and look to the future:

*‘I was in shock. ... I had a lot of problems in my life and, at that point, I thought, “I don’t want to live.” [If] I choose not to take medication, I would be gone. “Maybe that’s the best way,” I thought. But again, I have these small, my children were small ... when I came to Australia. And I have another four children ... And they all waiting for me. ... At that time, they were in Africa with my mum. So I had deep thoughts and I thought, “No, I can’t do it, you know. I have to stay alive for my children. I’ll have to stay alive for my mum. If I go, my mum, she will drop dead.” ... And I start medication.’* (Mizy)

Being separated from their children during the refugee process was a source of considerable uncertainty and distress for these women, in addition to coping with HIV.

The women who had been living with HIV for some time also had great concerns about staying alive. Without extended family in Australia, their children depended entirely on them:

*‘I never give up because of my children. ... I’m the only one. Without me, what’s going to happen?’* (Lena)

## Separation

Being separated from their children during the refugee process was a source of considerable uncertainty and distress for these women, in addition to coping with HIV. To give just one example here: Liya was diagnosed in a refugee camp in Africa and her application for refugee status was rejected. She insisted that her husband and her little daughter come to Australia (‘I push him for my daughter better life.’), while she stayed behind in the camp:

*‘It’s so hard, especially missing my daughter. So, so hard. ... I scared to one day die, not see my daughter. I was suffering for a long time.’* (Liya)

Seven years later, when Liya was finally able to come to Australia and be reunited with her family, her daughter no longer spoke her native language. Liya could not speak English, making communication with her daughter almost impossible:

*‘In the beginning it was so hard. It’s because she knows only her dad, plus she speak English. I’m not speak English when I arrive here and no communication. And I was really just like looking [at] my daughter, just –’* (Liya)

Domestic violence was another reason why a woman had to separate from her children. Monica was forced to separate from her husband because he was violent and sexually assaulted her. For her safety, Monica was relocated to another suburb while her daughter remained in the same area with a foster family so she could continue her education at the local school:

(Co-worker translating): *‘She wants to live again with her daughter because they’re not living together. ... When there was that problem of domestic violence, she separate from her husband*

and her daughter was still studying in the school. So she has to go to another place and she leave her daughter in [suburb]. ... She's living in a family house. ... And the son of the carers there are studying as well in the, in the [suburb] school, so -' (Monica)

## Disclosure

Disclosing to children was a difficult decision. For some women, their children's response was positive and the children were supportive. For others, disclosure was highly problematic. Even young children asked probing questions:

*'Now I want, I need to ask you one question. She's getting curious, why I keep going to the clinic and what type of medicine that I'm keep taking every day. ... So I don't have the answer. It's okay now but a little bit later, if she getting bigger, what I have to do?... If I telling her, she might not happy or she might be sad. ... At the moment, we just tell her that it's hepatitis medication.'* (Sophy)

Sophy: *'My daughter keep asking me, "Why both of you don't go to work?" ... I say, "No, I'm not, I'm not going to work," and she said, "If you don't go to work, you have no money."*

Co-worker: *'She have a concept of working from school.'*

Sophy: *'The other parent going to work but why not you?'*

The women described mixed responses when disclosing their serostatus to their children. Mizzy told her two youngest children when they were adolescents: *'These two, they know HIV is alright. They learn in school [in Australia]. So they never discriminate me.'* Her son encouraged her to meditate and to do yoga:

*'I think he was a really good help. From then I just went up and my CD count started to go ... which, it gave me an indication that I could be okay, you know. And I start to feel better.'* (Mizy)

Other women did not disclose to their children because they were worried about possible negative consequences for the children. Lena explained that one child was in high school and

another was at university. She wanted to wait until they had finished their studies. *'They might feel embarrassed to have a parent with this disease.'*

Aysha had difficulties raising her children as a sole parent. Her teenage daughter had run away from home, and her youngest child had ADHD. Because of this, she felt that disclosing her HIV status was simply was not an option:

(Co-worker translating): *'She can never discuss it with them. Especially the 19-year-old. ... She is concerned about their age. It's a hard age and she's been raising them alone. ... And like we always talk about how hard is it for her ... financially and being alone, especially with the little one having ADHD.'* (Aysha)

Disclosure to older children, who had grown up in Africa, caused problems and judgements grounded in cultural stereotypes from their country of birth:

*'I didn't keep my medicine, medication private. I just keep it in my cupboard. So they will go to my cupboard and they read it, and suspect, and didn't ask me, "Well -" They just start to have rumours on their own. Some of them attack me and start to accuse me that I was bad woman. Another one said, "I know Mum what you got. I know you got HIV and I know how you got it ... because you been running from my father." ... That's not the way I wanted to tell them. But they got that idea that I have HIV because of being "a bad woman".'* (Mizy)

Mizy, who had her serostatus disclosed by one of her children without her consent, describes an estranged relationship with her grown-up children, saying, *'We're distance.*

Religion make us distance with my [grown-up] kids.'

Liya had to disclose her status to her daughter when trying to explain her seven-year absence from her. Support and counselling were essential to helping her in this process:

*'Now she's good. She, now when she grown up, she understand everything, why I'm there [in Africa]. ... And when I come here, "Where you've been?" He [husband] never tell her [about HIV]. So finally I, I do. I used to do counselling. So it's really hard for me, my daughter and me communication, you know. So finally they told me to tell her why I was not here with her. So around when she was 14 I told her and it's really hard to see her. Just quiet. Then she stay in her room for whole day. Then just quiet, quiet for a week, for two weeks. And she not eating properly. She just watching me. But now she totally different. She really care about me.'* (Liya)

## New babies

Two women had babies after they had been diagnosed with HIV. Making decisions about pregnancy could cause considerable conflict between a woman's own wish not to have a child, her husband's wish and the cultural expectations to have a child, and advice by clinical staff against a pregnancy.

*'In the community, a lot of friend keep asking, "Why ... don't you have a child? You got married for long time." ... Twelve years after they married. And then they even call him a nickname that the person with no child. And so he feel like very shameful to say why I*

*continued overleaf*

Disclosing to children was a difficult decision. For some women, their children's response was positive and the children were supportive. For others, disclosure was highly problematic.

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*don't want to have it. ... But later on he say, "I don't want to keep any more secret. Have a child." ... And he said, "To satisfy myself because I'm going to die. After I die, I still have one child."* (Sophy)

(Co-worker translating): *'I tell social worker at [sexual health clinic D] that I want to get pregnant and they said that it's not good because of this, this, this ... but later on my husband he's insist that he want to have one. ... He insist and I don't want it because I'm still listen to the social worker about the risk of the child, yeah.'* (Sophy)

A big concern for these women was the baby's serostatus ("The first one year you're ... just praying every day, "Please, please, please.") Not being able to breastfeed was another concern. Margaret compared her experience of motherhood before and after her diagnosis:

*'It's so difficult being a mother with HIV because you don't breastfeed. You*

*have to use the bottle. ... those mothers who are not HIV, you just breastfeed your baby and it sleeps so nicely. A very nice sleep at night time when you breastfeed your baby. And if you are HIV, you need to make sure the bottles are so clean. You ... sterilise the bottles. ... You, you make sure at night time you wake even maybe even five times, going to, to give your baby milk.'* (Margaret)

### Conclusion and limitations

The size of this subsample of women is very small, and so not representative. However, the women's experiences raise a number of important issues.

The women described considerable pressure to remain strong in the face of a positive diagnosis, while also dealing with parenting issues. They frequently experienced disruptions to relationships with their children due to issues such as the refugee process, domestic violence, and cultural stereotyping of 'good' and 'bad' women; these things were a source of considerable distress. Disclosing their HIV status to their children was

difficult and could cause problems; however, as some women reported, if disclosure was done in a sensitive way, involving counselling, education and support – there could also be good outcomes.

**This project was a collaboration between the National Centre in HIV Social Research and the Multicultural HIV/AIDS and Hepatitis C Service.**

**Dr Henrike Körner is a Senior Research Fellow in the National Centre in HIV Social Research at the University of New South Wales.**

*Similar research examining the experience of CALD women living with HIV has also recently been conducted by the HIV Women's Program at Women's Health Statewide, South Australia. A series of community forums undertaken in 2011, uncovered a range of themes including some of the issues touched on in this article. A summary of comments from these forums is published in the online edition of HIV Australia, available at [www.afao.org.au](http://www.afao.org.au)*



**Pictured:** health workers and community leaders participating in the 'Doll-making for Community Leaders' workshop, held in Mirrabooka, Perth in 2011. A joint initiative of the WA AIDS Council, the Metropolitan Migrant Resource Centre, Mirrabooka and the Uthando Project, the workshop recommended doll-making as a way to break down 'complex cultural and social barriers' when discussing HIV and sexual health issues with community members. Photo: Natalija Brunovs. See our book review of *100 Dolls, Countless Hearts* on page 39.



# NAVIGATING THE JOURNEY: SHARING THE STORIES OF HIV-POSITIVE WOMEN

By James May

James May interviews Stefanie Christian, the coordinator of the Positive Women's Journey project, a new initiative of Positive Women Victoria that explores the value of sharing stories. He also speaks with two Victorian women about their experiences of living with HIV.

According to Stefanie Christian, the main objective of the Positive Women's Journey project is to produce a resource kit containing narratives about women's experiences of living with HIV and all the major issues that they face. The kit will be a collection of women's stories at various stages of their journey with HIV, and will also incorporate photography and artworks. While the project is primarily aimed at newly diagnosed women, it's also about connecting all HIV-positive women to support networks such as Positive Women Victoria.

The idea for the project was conceived by staff members of Positive Women Victoria who had knowledge of a similar project for women living with breast cancer. It will be the first of its kind in the HIV sector and seeks to target women from across the country, from various walks of life and cultural backgrounds. Participants will be recruited via AIDS organisations in each state. 'Sharing your story is powerful,' says Stefanie. 'It's part of the healing process. Breaking the silence removes the fear and lack of control from a situation. There are so many resources available to us, but this is about our personal experiences – what to expect, how to live well and knowing you're not alone. Everything from pregnancy to

medication, disclosure and relationships will be discussed. Hopefully it'll make the journey a whole lot easier.'

The journey kit seeks to cover issues spanning initial diagnosis to end of life and will include the following sections:

## 1. Coming to terms with your diagnosis

- What does it all mean and what now?
- Emotional and physical wellbeing
- Grief and loss
- Telling others
- Lifestyle changes

## 2. Treatments

- Be informed, knowing your options
- Finding the right specialist for you
- When to start and what to expect
- Side effects: emotional and physical and how to deal with them
- Natural/alternative therapies

## 3. Living with HIV

- Emotional health
- Physical wellbeing
- Sexual and reproductive health
- Relationships: parents, partners, friends, children
- Intimacy and sexuality
- Work/study
- Travel
- Children
- Navigating the medical landscape
- Stigma and discrimination
- Staying well

- Being connected
- Hospitals
- Dentists

## 4. Support and info

- Just for you: finding it, support online
- Getting involved
- For your significant others

## 5. Disclosure

- Partners
- Parents
- Children
- Friends
- Work/colleagues

## 6. Ageing and HIV

- What to expect
- Menopause
- Trials/research

## 7. End of life

- What you can do to prepare: services and care plans
- Wills and power of attorney

## 8. Tips for others

## 9. Resources

### Stefanie Christian's journey

Stefanie has been HIV-positive for twenty years. Now in her forties, she says that she can understand herself much better than when she was diagnosed at age 23, in 1992. She was staying in Bangkok at the time and says that she disappeared for three days on a drug and alcohol binge. 'I was using drugs and alcohol to deal with everything back then and it took ten years to get out of a black hole.'

Many HIV-positive people are afraid to disclose their status, according to Stefanie: 'It's about feeling dirty and infectious and the thought of someone finding out.' Stefanie led a swimming group for HIV-positive women for six years in Melbourne and says that it was heartbreaking to hear about the anxiety women suffered when disclosing their status. However, in recent times she's actually started observing far more serodiscordant couples in her peer-support networks.

*continued overleaf*

Stefanie fell pregnant to her husband of 16 years in Singapore in 1994, when there were no standards of 'best practice' in that country's maternity system. 'As soon as the gynaecologist saw HIV-positive on my records, he jumped back and screamed, "Oh God, you're HIV-positive." He put on double gloves for an ultrasound and told me he couldn't treat me anymore. I felt so low and dirty, like I was unworthy of medical treatment. I had different nursing staff who would sit on the other side of the room. One wouldn't help me to the bathroom. She made me squat in the bed and wouldn't even pass me a tissue.' Stefanie was given AZT for six months and she gave birth to an HIV-negative son in 1995.

She returned to Australia in 1996 which is when she first went to the Melbourne Sexual Health Centre (MSHC). 'I found it very friendly. It was light and warm and the staff treated me with dignity and respect. It was the first time I was told by a doctor that it was a manageable chronic illness and that made a huge difference.'

Stefanie has worked in the HIV sector for the last ten years and says that it's great to work closely with so many other HIV-positive people. 'I can share my fears and doubts and I don't have to live in fear of people finding out. It's been a big part of my healing.' Although she has found it heavy at times, it's given her the flexibility to have time off when her health is poor. 'Working in the HIV sector has given me a lot of confidence,' she says.

Stefanie says that becoming HIV-positive was like her 'resurrection.' 'You question what life is all about and what's important. You prioritise things and realise that life is precious. I always remember to be grateful for life and take pleasure in simple things.'

### **Stephanie Joy's journey**

Stephanie was born with the HIV virus in 1991 and has recently celebrated her twentieth birthday. She says that she

didn't really understand the meaning of the diagnosis until she was five: 'I was told that me and mum had something in our blood and that we couldn't tell anyone.' When she was twelve, Stephanie started meeting other HIV-positive children at 'Camp Good Time' – an annual retreat for positive young people and their families. 'I've been going ever since and I've found a great network of friends there. Sharing your story with others is priceless,' she says.

Stephanie says that it's been very hard to study at times. 'My body can't handle the stress and I have to take days off.' She also had to hide her HIV status from everyone at school aside from a trusted member of staff. She now studies social work on a part-time basis at university. 'I've found a good work/study balance,' she says. 'We're not the same as other people. We have to do things differently.'

Stephanie is a peer support worker at Positive Women Victoria and says that it's easy for some women to drop out of the community. She also does public speaking around the issue. 'I speak for those who don't have a voice. It's hard for positive kids to take control of their futures. Owning your story and talking about your struggles is powerful and it raises awareness of the issue.' Stephanie's first speech was at a NAPWA conference in Adelaide when she was twelve. 'I've been all over the world to speak at conferences and it's given me an interesting perspective on things. I'm grateful to have met these people.'

Stephanie has lipodystrophy and says that she never really feels comfortable in her body. 'I went on the meds when I was four and I get random rashes almost every day.' A doctor at a hospital in Melbourne recently told Stephanie that she was wasting a bed for checking in with a Golden Staph infection. 'He said that I had to expect these things living with HIV.' One of her best friends also walked out when she discovered Stephanie's HIV status.

'She said that I'd put her at risk. I can't control what people think but I have a saying now.' Those that matter do not mind, and those that mind do not matter.'

Stephanie feels like she's had to be an adult her entire life. 'I've never been able to be a kid and just play. Knowing you're mortal when you're young is sobering. I didn't have the same rights as other kids and I wanna make it better for the next generation.'

### **Heather Ellis' journey**

Heather was undertaking a world motorcycle journey when she contracted HIV in Africa at the age of 30. She was diagnosed in London in 1995 and was given five years to live. 'My story is not uncommon,' she says. 'I was a young Australian on a journey of a lifetime. In Mali, I was camped at the Bamako University when a man I'd met two weeks previously invited me to stay with his friends. I had a few beers and was later, not fully in control to ward off his advances. I naively put the experience behind me.'

Heather was not offered post-test counselling. However, she was informed about a support group for HIV-positive women in London. 'Some of the women had been HIV-positive for five years and they were still healthy. They inspired me to keep going.' Heather left the UK in 1996 to return home and she started to look and feel sick when she reached Central Asia. Her motorcycle adventure ended in Vietnam and she returned to Australia in late 1997.

'I had not told my parents I was HIV-positive. I didn't want to worry them and risk facing their rejection.' Instead, Heather explained her ill-health was due to a gastro bug she'd acquired in China. 'I knew I was dying. I advised my parents I'd found a job and a place to stay in Cairns but I contacted the hospital instead. I had AIDS and the medical staff held little hope for my survival. They insisted I contact my parents and asked if I



This 'River Of Life' mural was created as part of the 'Women's Day' event, held in December 2011 at the Positive Living Centre in Melbourne. The mural will be used as an illustration within the Positive Women's Journey Kit. The mural was produced by women as part of an artistic therapeutic session facilitated by Deirdre Byrne and Heather Morgan, two Care and Support Workers at the centre.

wanted to see the chaplain. I said no, insisting I was not going to die.' Fortunately, with the new generation of HIV medications, Heather's immune system recovered. Ten days later, she was home for Christmas, and began a Bachelor of Journalism in 1998. 'People underestimate the power of positive thought,' she says.

Heather says that she isn't worried about disclosing her HIV status. 'There are many serodiscordant relationships and this gives me confidence to tell men about my status. I don't fear disclosure as I'm writing a book about my motorcycle journey and my personal journey of living with HIV will be a part of it.' Heather is a member of PLWHA Victoria's Positive Speaker's Bureau and she recently spoke on World AIDS Day at Parliament Gardens in Melbourne. 'With nothing in the media reminding them that sexually transmitted infections (STIs), including HIV are out there, young

people don't realise the risks they're taking by having unprotected sex.'

To maintain her health, Heather says that she avoids stress. 'The most important thing is health and happiness and a holistic approach to achieving it.' Heather still loves to ride motorcycles and she is a motorcycle safety advocate with the VicRoads motorcycle advisory group. She is also a board member of Positive Women Victoria and a widely-published freelance writer.

Heather says that HIV has made her life richer in many ways. 'After 17 years of being HIV-positive, I can educate others to take more care. What I say can change lives. If I can help one person then I've done a good deed.'

### The value of sharing stories

These women have gained a great deal of personal growth from sharing their stories. Voicing their experiences of living with HIV continues to be an

important part of their healing process. It's brought them in touch with other positive women and changed their perspectives on living with the virus in empowering ways. They've also been able to tackle public speaking roles where they advocate for the positive community and inform the public about the reality of living with HIV. The Positive Women's Journey project will be another important step in the personal and community development of HIV-positive women around the country.

**The Positive Women's Journey kit will be available from specified clinics and HIV/AIDS organisations around the country in 2012.**

**James May is a freelance writer in Melbourne and regularly contributes work to the HIV sector in Victoria. He has also written for various magazines including MCV, Positive Living and HIV Australia.**

# WOMEN, HIV AND AGEING: SOME SPECIFIC CHALLENGES

By Mia Dawson

Thirty years on from the first reports of HIV and AIDS, and following the advent of antiretroviral therapies, HIV is now considered to be a chronic, manageable disease rather than a critical illness. Today, people living with HIV receiving treatment can expect a near-normal lifespan – something that many of us could not imagine living to see! With the focus now on maximising longevity and quality of life, growing old and navigating all that the ageing process entails is now a reality for many HIV-positive people.

In addition to the health issues experienced by the ageing population as a whole, women living with HIV face some specific challenges as they age. While much has been written on the social and cultural differences that affect how women manage HIV, from a research perspective little is understood about the long-term effects of the antiretroviral drugs (ART) on women's physiology, or the physical and emotional effects of ageing specific to HIV-positive women. This article focuses on the physical and emotional aspects and consequences of living longer with HIV as experienced by women.

Women are under-represented in the majority of clinical studies, such that effective gender comparisons are not possible. Of all clinical trials between 2000 and 2008, only 20% of participants were women.<sup>1</sup> Historically, drug regimens were tested on men, and due to biological differences between women and men – such as weight and fat distribution – women may, in effect, receive a higher dose of a drug in their

blood level because they generally weigh less. There are also biological differences between men and women in how medicines affect the body and the way in which it metabolises these. This is also important where women are living longer with HIV and need to take other medications which may alter the metabolic action of some drugs, such as hormone replacement therapy. There is a need for more women-specific and comparative studies to explore and address some of these issues.

## Physical challenges of ageing in women with HIV

### Menopause

There is a growing body of evidence that suggests that women living with HIV have an earlier onset of menopause than their HIV-negative counterparts.<sup>2</sup> This has implications for other health issues affecting women as a result of entering menopause at a younger age. The onset of menopause is associated with an increased risk of cardiovascular disease (CVD), high blood cholesterol levels, diabetes and osteopenia and osteoporosis.<sup>3</sup> The early onset menopause (before 46 years) is associated with an increased risk of these diseases and may be linked to increased mortality.<sup>4</sup>

Although women living with HIV were 73% more likely to experience an early onset of menopause when compared with HIV-negative women<sup>5</sup>, there is a distinct data gap between the research on the early onset of

menopause and HIV. There are a number of factors that can contribute to the early onset of menopause; potential contributors to the early onset of menopause in women with HIV are: immunosuppression (a lower CD4 count); smoking (menopause can occur up to 1–2 years earlier in smokers, compared with non-smokers); and socioeconomic status (markers of low socioeconomic status such as a lower level of education, unemployment and/or poverty have been associated with early menopause onset).<sup>6</sup>

Many of the symptoms associated with menopause such as hot flushes, fatigue or insomnia can also be associated with HIV, so women need to monitor these changes in consultation with their health professional. In addition, women have complications with drug interactions between ART and hormone replacement therapy (HRT) prescribed to relieve the symptoms of menopause. Antiretroviral medications have been shown to reduce the effectiveness of HRT (oestrogen and progesterone), and oestrogen can also cause decreased levels of ART resulting in an increased viral load and resistance issues.<sup>7</sup>

### Osteoporosis

There is an increased risk of osteoporosis in women living with HIV. Recent studies have shown that people living with HIV have a lower bone mineral density and this is compounded in women, particularly around the onset of menopause. However, the causes of this decrease in bone mineral density are unclear and may be due to HIV itself or to antiretroviral drugs. Additionally, vitamin D deficiency is common in women living with HIV and may be exacerbated by the onset of menopause.<sup>8</sup> It is recommended that women have a DEXA scan ('dual energy x-ray absorptiometry' used to measure bone mineral density) every two to five years. There are also FRAX (Fracture Risk Assessment) calculation tools that assess bone health; many are available online.<sup>9</sup>



## Cardiovascular disease

Women with HIV – particularly those on ART – may be at an increased risk of cardiovascular disease (CVD). Studies suggest that antiretroviral medications such as some protease inhibitors (PI) and non-nucleoside reverse-transcriptase inhibitors (NNRTI) can increase the risk of heart problems by raising the levels of cholesterol and triglycerides in the blood. Researchers have also noted that there is a higher CVD incidence with interruption versus continuous highly active antiretroviral therapy (HAART). However, other research suggests that it may be HIV itself that causes heart problems.<sup>10</sup> Historically, health professionals have tended to focus on cardiovascular disease amongst men, but given that CVD ‘is the main killer of older women’<sup>11</sup> worldwide there needs to be an increased focus on women’s health in this respect.

## Cancer

There is an increased risk of non-AIDS defining cancers in women living with HIV, such as cancers of the lung, oesophagus, multiple myeloma, oral cavity and pharynx, Hodgkin’s disease, leukemia, and rectal/anal cancers. There is also an increased risk of human papillomavirus (HPV) tumours and cervical cancer. However, researchers have not discerned an increased risk of breast cancer in women living with HIV. It would also appear that HAART regimens significantly reduce the risk of AIDS-defining cancers, and drug–drug interactions between cancer drugs and ART can be predicted and managed.<sup>12</sup>

## Renal disease

Age is one of the major risk factors for renal disease in women aged 45 years and over, and women living with HIV may be at an increased risk for acute renal failure or chronic kidney disease.<sup>13</sup>

## Frailty

In order ‘to define frailty as an independent syndrome (or phenotype), three of the following criteria need

to be present: unintentional weight loss; self-reported exhaustion; low physical activity; slowness measured by time taken to walk three metres; and weakness measured by grip strength.

For women living with HIV, severe CD4 cell depletion is an independent predictor of slowness, weakness, and frailty. Women who have a CD4 count <100 cells/mm<sup>3</sup> have a 2.7 times higher prevalence of frailty ... Hospitalisation rates are greater for frail persons, with a five-fold longer duration of inpatient stay’.<sup>14</sup>

## Emotional, psychological and psychiatric challenges of ageing in women with HIV

### Neurocognitive disorders

Neurocognitive changes associated with HIV consist of cognitive, behavioural and motor dysfunctions, and have a tendency to increase with age in people living with HIV. While neurological impairment is present in over 50% of HIV-positive people, neurological dysfunction, including memory impairment and psychomotor function, has been shown to be increased in women with HIV. A recent study of HIV-positive women just entering middle age, ‘has found an association between carotid artery disease and neurocognitive impairment. Among HIV-negative people, such impairment does not usually appear until at least 15 years later.’<sup>15</sup>

There is much debate over the association of HIV with the increased incidence of early onset dementia and an increased risk of Alzheimer’s disease. However HIV-associated dementia is known to increase with age.<sup>16</sup>

## Depression and anxiety

In findings released in January 2012 at the 2nd International Workshop on HIV and Women, researchers concluded that ‘women living with HIV are more likely to suffer from depression than HIV-positive men.’<sup>17</sup> The study’s findings included that ‘the percentage of women who met the criteria for depression did not differ significantly between those who were taking antiretrovirals and those who were not. However there was a significant difference in depression rates, antiretroviral use and gender: 10.6 percent of the men living with HIV who were not on AIDS meds met the criteria for depression versus 20.8 percent of the women living with HIV who were not on treatment. [Furthermore], a higher proportion of women than men screened positive for anxiety, and more women than men suffered from both depression and anxiety.’<sup>18</sup>

*continued overleaf*

Research has suggested that older women may not perceive themselves to be at risk from HIV and therefore often present as a late diagnosis.

## Family and parenting issues

Research has suggested that older women may not perceive themselves to be at risk from HIV and therefore often present as a late diagnosis. In addition to the health complications that a late diagnosis often entails, older women face many different social and cultural challenges surrounding living with HIV.

Older women often have a dual role of caring for their own health while also caring for children, grandchildren or elderly parents, and are more likely to have issues around disclosure to their children. Many may have delayed starting a family due to HIV only to find subsequent complications affecting parenthood due to the early onset of menopause.<sup>19</sup>

## Support

A recent article published in the *Medical Journal of Australia* has suggested that Australians with a chronic illness or disability face serious levels of economic hardship. The authors state that 'the available evidence indicates that the out-of-pocket costs of treatment and self-management and loss of income from chronic illness and disability are associated with economic hardship, catastrophic health care spending and non-compliance with medical treatment.'<sup>20</sup> It would not take much to extrapolate this research to older women living with HIV. Gender-related barriers including social and economic determinants have long affected women living with HIV. 'Women may face barriers due to their lack of access to and control over resources, child-care responsibilities, restricted mobility and limited decision-making power.'<sup>21</sup> Healthcare professionals and community advocates have suggested that 'older women living with HIV may require more health care and emotional support than those without HIV. [They point to] financial circumstances and support from a

partner may be decreased with older women with HIV, [and that women have a] double role of caring for ailing parents or coping with parental loss. Feelings of stigma and isolation are still common among ageing women with HIV, and information available to women with HIV about ageing is limited with regard to what is due to the disease and what is due to the normal ageing process.'<sup>22</sup>

## Summary

Women living with HIV face many potential physical and emotional health issues as they age. However, it has been suggested that with the appropriate interventions, lifestyle choices and integrated support from health care professionals and community groups, the impact of these challenges can be effectively managed.<sup>23</sup> The question is whether there is the political and collective will to ensure that older women's physical and emotional wellbeing is adequately supported through their journey with HIV.

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## References

- 1 Struble, K., Soon, G., Min, M., et al. (2009). *Meta-analysis of efficacy outcomes for treatment-naïve and treatment-experienced HIV-infected women in randomized controlled clinical trials: 2000 to 2008*. 16th Conference on Retroviruses and Opportunistic Infections, Montreal, abstract 987b, 2009.
- 2 Evans, D. (2009, 28 July). *Menopause May Occur Earlier in HIV-Positive Women*. Retrieved from: [http://www.aidsmeds.com/articles/hiv\\_women\\_menopause\\_1667\\_16997.shtml](http://www.aidsmeds.com/articles/hiv_women_menopause_1667_16997.shtml)
- 3 Women for Positive Action Resource Centre (WPARC). (2009). *HIV and Ageing*. Women for Positive Action. Retrieved from: [www.womenforpositiveaction.org/resources/educit.cfm](http://www.womenforpositiveaction.org/resources/educit.cfm)
- 4 *ibid.*
- 5 Schoenbaum, E., Hartel, D., Lo, Y., et al. (2005). HIV infection, drug use, and onset of natural menopause. *Clin Infect Dis*. 41(10),1517–24. [Epub] 2005, Oct 13. Retrieved from: <http://www.ncbi.nlm.nih.gov/pubmed/16231267?dopt=Abstract>
- 6 WPARC, op. cit.

- 7 The Well Project. (2011). *Menopause and HIV*. Retrieved from: [http://www.thewellproject.org/en\\_US/Womens\\_Center/Menopause.jsp](http://www.thewellproject.org/en_US/Womens_Center/Menopause.jsp)
- 8 Arnsten, J., Freeman, R., Howard, A., et al (2006). HIV Infection and Bone Mineral Density in Middle-Aged Women. *Clinical Infectious Diseases*, 42(7), 1014–1020. Retrieved from: <http://cid.oxfordjournals.org/content/42/7/1014.short>
- 9 For example see the World Health Organization's FRAX tool. Retrieved from: <http://www.shef.ac.uk/FRAX/>
- 10 CATIE. *Managing your health: a guide for people living with HIV*. 18. HIV and Ageing. Retrieved from: <http://www.catie.ca/en/practical-guides/managing-your-health-guide-people-living-hiv/18-hiv-and-ageing>
- 11 World Health Organization (WHO). (2009). *Women's health*. Fact sheet No.334. Retrieved from: <http://www.who.int/mediacentre/factsheets/fs334/en/index.html>
- 12 WPARC, op. cit.
- 13 Szczec, L., Hoover, D., Feldman, J., et al. (2004). Association between Renal Disease and Outcomes among HIV-Infected Women Receiving or Not Receiving Antiretroviral Therapy. *Clinical Infectious Diseases*, 39(8), 1199–1206. Retrieved from: <http://cid.oxfordjournals.org/content/39/8/1199.full.pdf>
- 14 WPARC, op. cit.
- 15 Hosein, S. (2011, 11 November). *Study in HIV-positive women links heart health to brain functioning*. Retrieved from: <http://www.catie.ca/en/catieneews/2011-11-11/study-hiv-positive-women-links-heart-health-brain-functioning>
- 16 WPARC, op. cit.
- 17 Terrell, K. (2012, 13 January). *Depression More Common Among Women Than Men Living With HIV*. Retrieved from: <http://www.thebody.com/content/65396/depression-more-common-among-women-than-men-living.html>
- 18 *ibid.*
- 19 WPARC, op. cit.
- 20 Jan, S. et al. (2012, 16 January). *Falling through the cracks: the hidden economic burden of chronic illness and disability on Australian households*. Retrieved from: <http://sydney.edu.au/news/84.html?newsstoryid=8486>
- 21 WHO and UNAIDS. (2008). *Gender Inequalities and HIV*. Retrieved from: [http://www.who.int/gender/hiv\\_aids/en/](http://www.who.int/gender/hiv_aids/en/)
- 22 WPARC, op. cit.
- 23 *ibid.*

**Mia Dawson is an advocate for women living with HIV, and has been involved and volunteered in the HIV/AIDS sector in Australia and overseas for approximately seventeen years. She is committed to raising visibility around the issue of women and HIV, and believes that education and creating awareness within the wider community is vital to achieving this.**

# ANTI-TRAFFICKING, SEX WORKERS' RIGHTS AND HIV PREVENTION

By Jules Kim

Sex workers in many states of Australia are under threat from proposed law reform that seeks to remove existing legal and policy frameworks that have been crucial to Australia's successful HIV response. Much of this legislation has been introduced under the guise of preventing people trafficking. Although trafficking is not the experience for most people working in the Australian sex industry, ill-informed and speculative perceptions about trafficking are frequently used as an excuse to increase regulation and criminalisation of the sex industry.

## Australian responses to anti-trafficking

The anti-trafficking response, and associated media hysteria – non unlike the hysteria that surrounded AIDS in the early '80s – has given authorities permission to overstep the fair and reasonable application of Australian law, particularly in relation to culturally and linguistically diverse (CALD) sex workers. For example, laws proposed in Western Australia seek to prevent all those who are not a permanent resident or an Australian citizen from working in the sex industry; this would preclude all people on temporary visas from legally undertaking any form of sex work, even if their visa conditions allowed them to work, and even though sex work is not illegal.<sup>1</sup>

In Victoria, following a spate of media reports about trafficking (including a joint 'investigative' report by the ABC, *The Age* and the *Sydney Morning Herald*), the *Sex Work and Other Acts Amendment Bill 2011*<sup>2</sup> was introduced.

Despite consistent and systemic evidence of police corruption that clearly demonstrates that police are inappropriate regulators of the sex industry<sup>3</sup>, the Bill proposes to revert sex industry regulation from Consumer Affairs to the Victoria Police and to 'improve the powers of Victoria Police to investigate and enforce'<sup>4</sup>. Similarly, the NSW Liberal Government recently announced its intention to proceed with the removal of the best practice model of decriminalisation – which has been in place in NSW since 1995 – and to introduce a tougher licencing system for brothels which they state is in response to 'sex trafficking and criminal involvement in the industry.' This is contrary to findings of the Wood Royal Commission that decriminalisation in NSW would 'close off' potential opportunity for 'corrupt conduct on part of the police'.<sup>5</sup> Evidence shows that decriminalisation in NSW has delivered the most effective public health outcomes in the state since its implementation.<sup>6</sup>

The *Sixth National HIV Strategy 2010–2013* supports decriminalisation as a priority action to identify and address the legal barriers to evidence-based prevention strategies across jurisdictions, as a way to achieve human rights and anti-discrimination outcomes. The National Strategy recognises that decriminalisation and deregulated legislative frameworks give sex workers increased control over our work and helps to achieve better health and HIV outcomes: 'The priority is to ensure that legislation, police practices and models of regulatory

oversight support health promotion, so sex workers can implement safer-sex practices and the industry can provide a more supportive environment for HIV prevention and health promotion.' Conversely, restrictive legal frameworks present barriers to health promotion service delivery, especially to those from intersecting priority populations such as CALD and migrant sex workers.

Sex workers who speak out against anti-trafficking responses have been accused of refusing to see the 'dark side' of the sex industry. We know that like any other industry, sex workers can face good and bad work conditions. When criminalised, sex workers who do experience exploitation or trafficking fear seeking justice for fear of being prosecuted. Current anti-trafficking responses are not addressing the causes of trafficking and have scapegoated sex workers. The 2011 report of the UNAIDS Advisory Group on HIV and Sex Work states, 'The frequent failure of policy-makers, religious leaders and society to distinguish sex work from human trafficking has sometimes led to involuntary displacement, harassment or detention of sex workers. Violence against sex workers is too often committed with impunity by state and civilian actors, exacerbating sex workers' HIV vulnerability.' The reality is that trafficking is not the experience for most people in the sex industry. Sex work is not inherently exploitative and, like other workers, sex workers travel and migrate for work; migration for sex work does not cause trafficking. Evidence shows that criminalisation or over regulation of the industry will only serve to isolate sex workers creating further difficulties for sex workers to access justice in the event of a crime.

## Genesis of the global anti-trafficking moment

In recent years, there has been a disturbing renewal of focus on trafficking internationally that ignores evidence and continues to equate sex work with sexual exploitation and

*continued overleaf*

trafficking with the movement of people for sex work. Organisations worldwide have sprung up as experts in trafficking and the sex industry. Scarlet Alliance have received anecdotal reports from Empower Foundation, a sex worker organisation in Thailand, that many religious organisations have reinvented themselves as trafficking organisations. A cursory search on the internet will yield numerous websites from religious and feminist anti-trafficking organisations ready to rescue us from the sex industry.

At the XVth Bangkok World AIDS Conference in 2004, sex workers from 20 countries reported the negative impacts of the anti-trafficking lobby on sex worker rights globally.<sup>7</sup> Where did this anti-trafficking movement come from? In October 2001, the US President George W Bush, created a bureau in the State Department – the Office to Monitor and Combat Trafficking in Persons – as a result of the passing of the *Trafficking Victims Protection Act* (TVPA) of 2000. The Office produces an annual report card for countries called the *Trafficking in Persons Report* or the TIP report.<sup>8</sup> The TIP report divides nations into tiers based on their compliance with standards outlined in the TVPA. These tiers are described on the state department website as:

- **Tier 1 Countries** whose governments fully comply with the TVPA's minimum standards.
- **Tier 2 Countries** whose governments do not fully comply with the TVPA's minimum standards, but are making significant efforts to bring themselves into compliance with those standards.
- **Tier 2 Watchlist Countries** whose governments do not fully comply with the TVPA's minimum standards, but are making significant efforts to bring themselves into compliance with those standards AND:

a) The absolute number of victims of severe forms of trafficking is very significant or is significantly increasing; or b) There is a failure to provide evidence of increasing efforts to combat severe forms of trafficking in persons from the previous year; or c) The determination that a country is making significant efforts to bring themselves into compliance with minimum standards was based on commitments by the country to take additional future steps over the next year.

- **Tier 3 Countries** whose governments do not fully comply with the minimum standards and are not making significant efforts to do so.

Governments of Tier 3 countries '... may be subject to certain sanctions, whereby the US government may withhold or withdraw non-humanitarian, non-trade-related foreign assistance. In addition, countries on Tier 3 may not receive funding for government employees' participation in educational and cultural exchange programs. Consistent with the TVPA, governments subject to sanctions would also face US opposition to assistance (except for humanitarian, trade-related, and certain development-related assistance) from international financial institutions such as the International Monetary Fund (IMF) and the World Bank.'

The TVPA recommends the criminalisation of the sex industry as an effective means to combat trafficking. Following on from US political pressure, some countries in the region have introduced the model of criminalisation, South Korea is one example. Sex workers in South Korea report being arrested – their workplaces being forcibly closed down, with red light districts disappearing almost overnight. This has created the additional push for sex workers to migrate in order to work in their chosen

profession. The US anti-trafficking solution in the form of criminalisation of sex work has been a major factor in creating an environment where trafficking can occur.

This conflation of migration for sex work and trafficking has been extended into policies requiring US government funds to be prohibited from going to organisations, such as non-government organisations (NGOs), who do not explicitly oppose sex work and demonstrate this by the signing of the 'anti-prostitution pledge'. Maria McMahon considers that 'NGOs working with sex workers understand that access to sex workers is enhanced by taking on positions that call for the decriminalisation or legalisation of sex work. Many organisations have ceased applying for US funding, or have closed down US funded parts of their services aimed at sex workers, in order to keep meaningful relationships with the sex workers they hope to reach. In an extraordinary reaction to the problematic US policy, Brazil turned down 18 million US dollars of HIV/AIDS funding, rather than accept sanctions on what they could offer to their own people and sex workers in particular.'

In addition to the push for migration via the US TIP report, conditions for trafficking are exacerbated by Australia's discriminatory immigration policies that favour 'skilled' migration from industrialised countries and create a lack of opportunities for sex workers to migrate legally. Providing safe, legal channels for sex workers to migrate to Australia and equitable access to visas would reduce the need for sex workers to incur substantial debts and engage third party agents in order to travel and work. Currently there is a dearth of translated materials and information on visa access and conditions, industrial and human rights, relevant laws and justice mechanisms. Translating and increasing access to this material is a simple and effective means to prevent



trafficking. Adequate funding to support multilingual peer education through CALD projects within sex worker organisations, the provision of translated resources, and community engagement will strengthen the human, civil and political rights of migrant sex workers and increase our autonomy, agency and self-determination. This is a key step to addressing trafficking.

### **Ending exploitation: sex workers need rights-based approaches, not criminalisation**

Attempts to use trafficking to abolish the sex industry undermine any real efforts to address trafficking and labour exploitation. Current anti-trafficking interventions have focused on surveillance of the sex industry and prosecution and deportation of migrant sex workers. These have been unsuccessful in assisting workers who experience labour exploitation and trafficking-like work conditions and have impacted negatively on the rights of all sex workers. The negative policy outcomes, including increased criminalisation of sex workers, will have sustained, long term negative impacts.

Preventative, rights-based approaches that address the circumstances that create trafficking should be pursued over criminal justice approaches. The most successful approaches prioritise the needs, agency and self-determination of trafficking victims over criminal prosecutions and increased surveillance, and ultimately result in the best outcomes.

Sex workers want decriminalisation. Decriminalisation is the internationally recognised best-practice approach to sex industry regulation and is supported by the United Secretary General Ban Ki Moon, UNAIDS, the UN Population Fund, and the Australian Government's National HIV and STI Strategies. Rather than trafficking, Korean sex workers at ICAAP 10 in South Korea report anti-trafficking responses as

having the greatest negative impact to their lives and livelihood and called for the decriminalisation of sex work. Further, they report that because peer sex worker organisations are illegal, and because being a known sex worker results in harassment and almost certain arrest, working effectively as a peer-based organisation is very difficult. The *UNAIDS Guidance Note on HIV and Sex Work 2009* observes: 'In many countries, laws, policies, discriminatory practices, and stigmatising social attitudes drive sex work underground, impeding efforts to reach sex workers and their clients with HIV prevention, treatment, care and support programmes ... Stigma and discrimination must be effectively addressed; violence and abuse of sex workers must be reduced; and legal barriers to participation should be revised. Achieving the changes in social and legal conditions that limit access to [HIV] services will take time, but it is critical to implement needed legal and policy reforms now.'<sup>9</sup>

When sex work is decriminalised sex workers can choose when, where and how we work. Decriminalisation results in the best outcomes for all sex workers – including those who are affected by trafficking and exploitation can seek support without fear of arrest. Additionally, the rights of migrant workers must be recognised. Migrant sex workers need equitable access to support, Australian justice mechanisms, arbitration processes and industrial rights protections without fear of arrest or deportation.

Australia's successful HIV response has been supported by the enabling legal environments in many states. However this trend to respond to trafficking through criminal and legal sanctions means we are entering a new phase with states criminalising sex work. This is in direct opposition to what we know about effective HIV prevention. Meaningful consultation with sex workers has been crucial to successful health promotion approaches

and applies equally to the issue of trafficking. Sex workers must have meaningful involvement in developing, monitoring and implementing policy development and law reform. Supporting the rights, autonomy and self-determination of migrant sex workers through the decriminalisation of sex work is the most effective way to prevent trafficking and labour exploitation.

### **References**

- 1 *Draft Prostitution Bill 2011*. 2nd reading moved by WA Attorney General Mr C C Porter at Assembly 12.20pm on 3/11/11. Retrieved from: [http://www.department.dotag.wa.gov.au/\\_files/Prostitution\\_Bill\\_2011.pdf](http://www.department.dotag.wa.gov.au/_files/Prostitution_Bill_2011.pdf)
- 2 *Sex Work and Other Acts Amendment Bill 2011*. Retrieved from: <http://www.lawalert.info/au/legislation/vic-bills-sex-work-and-other-acts-amendment-bill-2011>
- 3 Parliament of New South Wales. (1986). *Report of the Select Committee of the Legislative Assembly upon Prostitution* (Chairman: P Rogan). Parliament of NSW, Sydney.
- 4 Government of Victoria. (2011). *Sex Work and Other Acts Amendment Bill 2011 Explanatory Memorandum*. Retrieved from: [http://www.austlii.edu.au/au/legis/vic/bill\\_em/swaoaab2011335/swaoaab2011335.html](http://www.austlii.edu.au/au/legis/vic/bill_em/swaoaab2011335/swaoaab2011335.html)
- 5 Royal Commission into the New South Wales Police Service. (1987). *Final Report. Volume 1: Corruption*. Commissioner: The Hon Justice JRT Wood, 13. Retrieved from: <http://www.pic.nsw.gov.au/files/reports/volume1.pdf>
- 6 Donovan, B., Harcourt, C., et al. (2010). Improving the health of sex workers in NSW: maintaining success. *NSW Public Health Bulletin*, 21(3–4): 74–77. Retrieved from: [http://www.publish.csiro.au/?act=view\\_file&file\\_id=NB10013.pdf](http://www.publish.csiro.au/?act=view_file&file_id=NB10013.pdf)
- 7 Fawkes, J. (2004). Sex Work and Empowerment, *HIV Australia*, 4(1), September–November.
- 8 For access to the *Trafficking in Persons Report 2011*, see: <http://www.state.gov/j/tip/rls/tiprpt/2011/>
- 9 Joint United Nations Programme on HIV/AIDS (UNAIDS). (2009). *UNAIDS guidance note on HIV and sex*. Retrieved from: [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20111215\\_Report-UNAIDS-Advisory-group-HIV-Sex-Work\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20111215_Report-UNAIDS-Advisory-group-HIV-Sex-Work_en.pdf)

**Jules Kim is Migration Project Manager at Scarlet Alliance, Australian Sex Workers Association.**

# TRANSGENDER WOMEN AND HIV: A FOOTNOTE TO THE EPIDEMIC

By Abigail Groves

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At the bottom of page 36 of the 2011 *Annual Surveillance Report on HIV and STIs* there's a footnote. By the end of 2010, 30,486 people had been diagnosed with HIV in Australia. Most – 27,701 (over 90%) – were men, with another 2,459 women.<sup>1</sup> The footnote explains why these figures don't add up: they include 250 diagnoses for which no sex was reported, and 76 people whose sex was reported as transgender. This article is about that footnote, and the people it does or does not represent.

An article about transgender women and HIV in Australia risks becoming an article about a vacuum, because extremely little has been written about HIV and transgender women – or transgender people in general – in this country. Transgender academic Roberta Perkins completed a national needs assessment of transgender people in 1994. Funded by the Commonwealth Department of Health and auspiced by the Australian Federation of AIDS Organisations, this was a major study of transgender health with 146 participants

from around Australia, which is no small achievement.<sup>2</sup> But most of its recommendations were ignored, and there has been no comparable research since. The 2007 *Tranznation* report surveyed 253 transgender men and women from around Australia and New Zealand, but did not collect data about HIV or sexual health.<sup>3</sup>

The paucity of research is disappointing, as transgender people are at increased risk of acquiring HIV. Some of the statistics from around the world about HIV prevalence among transgender people – which usually relate to transgender women – are frankly alarming. In the US, one study estimated HIV prevalence among transgender women at 27.7%.<sup>4</sup> In other countries, particularly in the developing world, it is even higher. These high levels of HIV are usually attributed to the extreme social and economic marginalisation of transgender women, who have high levels of engagement in sex work – often the only work available to them.<sup>5</sup> It seems unlikely

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that prevalence would be as high among transgender women in Australia, simply because levels of HIV in Australia as a whole are comparatively low – only a fifth of those in the United States, for example. Australian sex workers have also been very effective in promoting high levels of condom use. Yet it is impossible to be certain about prevalence because there is little research, and what data is available is of poor quality.

So what can we say for certain about transgender women and HIV in Australia? In short, the answer is 'very little'. The footnote in the Kirby Institute's 2011 *Surveillance Report* mentions 76 diagnoses of HIV where the sex of the patient was listed as 'transgender' have been made in Australia. This figure is almost certainly incomplete, for a number of reasons. First, it is not clear whether these 76 people are men or women. The notification forms that doctors complete when they make a diagnosis of HIV do include 'transgender' as an option, which makes them quite progressive in comparison to most forms, but they don't differentiate between transgender men and transgender women. This is because the subtleties of the distinctions between 'male', 'transgender woman', 'transgender man' and 'female' – with their corresponding variations in bodies, stages of transition and identity – are too complicated for a simple notification form.<sup>6</sup> However, it is likely that most – possibly all – were transgender women. Available studies of HIV among transgender populations from around the world indicate much higher levels of prevalence among trans women than among trans men.<sup>7</sup> This also makes sense in cultural terms, as transgender women may have a background in the gay community, whereas transgender men often have a background in the lesbian community. Transgender women are also more likely to engage in sex work. Together, these two factors make for a higher level of HIV risk among trans women.

The second limitation of the surveillance data is that transgender status has been included on notification forms only since the early 1990s. It seems that there were some cases recorded before this, but probably not all; one study, conducted in 1990, of 77 transgender women in Sydney found that 15 had HIV.<sup>8</sup> The 2010 Surveillance Report records 23 deaths among transgender people;<sup>9</sup> those that died are likely to have been diagnosed earlier. This figure, incidentally, translates to 0.3% of AIDS deaths in Australia.

More importantly, HIV surveillance forms are completed by doctors rather than patients. Of course doctors talk to their patients, and rely on the information they are given. But they don't always ask, 'are you male or female?', particularly when the answer seems obvious. Yet the correct answer is not always the obvious one and due to high levels of discrimination in health services, transgender people may choose not to disclose.<sup>10</sup>

For all these reasons, it is not possible to ascertain the incidence of HIV among trans women with any certainty. Prevalence is even more difficult, because the size of the transgender population is basically unknown. Estimates of the prevalence of transsexualism vary enormously, largely because of the very different criteria used to define a 'transsexual', and there have been no real attempts to count the transgender population in Australia.<sup>11</sup>

Those studies that do exist often focus on a particular service or location, such as the number of transgender people attending a particular service. For instance, in 2007 the Sydney Sexual Health Centre (SSHC) audited its case files to find transgender people who had attended the service over a 16 year period. It found just 40 transgender people (36 women and 4 men) had attended the service, out of over 70,000 clients seen during the period. The researchers acknowledged that not all transgender clients would have been

identified in case notes, and not all would have disclosed their transgender status, but the actual number would still have been quite small.<sup>12</sup>

Nonetheless, the researchers were able to make some interesting observations about their transgender clients. They called the transgender group 'dichotomous', because fully half of the transgender women reported having no sexual contact with anyone in the previous twelve months, whereas the other half had disproportionately high rates of injecting drug use, high numbers of sexual partners, and high rates of sex work. 44% of the transgender women had done sex work at some point, and 28% were working when they visited the service.<sup>13</sup> This proportion is almost identical to that reported by Perkins in 1994.<sup>14</sup> Perkins called sex work 'a fact of life' for many transgender women, who are subject to extreme social and economic marginalisation.<sup>15</sup> She reported that transgender sex workers are more likely to rely on street-based work, less likely to use condoms consistently, and more likely to suffer sexual or other assaults.<sup>16</sup>

It is this group of transgender sex workers who concern HIV educators. Four of the women in the Sydney Sexual Health Centre study were HIV-positive, though there was no record of how they acquired HIV. In fact, this information is not recorded in epidemiological reports. The mode of transmission in cases of HIV among transgender people is usually listed

as 'undetermined', because of the difficulties of determining whether sex was 'male-to-male' or 'heterosexual'.<sup>17</sup> With such limited information, and such a small group, it's almost impossible to detect trends. HIV services may be justifiably concerned about high levels of risk behaviour among some transgender sex workers, but it's important to be cautious in making generalisations about transgender women as a group, or even transgender women with HIV.

For those transgender women living with HIV, isolation is a big problem. Jan, an HIV-positive trans woman interviewed for this article, did not access HIV services at all, saying, 'It's all about the gay guys. There aren't really a lot of services for women with HIV and the ones that are there don't really make you feel welcome. And the gay guys definitely don't, so you are really on your own.'<sup>18</sup> However, she did have a regular GP, who worked from a high caseload practice in the inner city, and said, 'They know their stuff and they treat you pretty well.' The Tranznation study also noted that transgender people were very appreciative of those doctors who were considered supportive.<sup>19</sup>

However, Jan avoided GLBT services, citing bad experiences. 'A lot of places say they are GLBT but they don't really do anything for trannies,' she said. 'They don't make you feel comfortable. It's

*continued overleaf*

The mode of transmission in cases of HIV among transgender people is usually listed as 'undetermined', because of the difficulties of determining whether sex was 'male-to-male' or 'heterosexual'.


stressful and I come away feeling worse than when I went there. I don't want that.' More worryingly, Jan reported that 'trannies don't go to those services'. This suggests that marginalisation of transgender people is a problem not confined to the mainstream community.

By contrast, Jan spoke highly of the Gender Centre in Sydney, though it is not actually an HIV service. The need for specific services for transgender people was cited by Perkins in 1994, but the Gender Centre remains the only funded service in Australia specifically for transgender people. With little change over that time, it seems likely that transgender women like Jan will remain a footnote to the story of HIV in Australia.

## References

- 1 The Kirby Institute. (2011). *HIV, viral hepatitis and sexually transmissible infections in Australia: Annual Surveillance Report 2011*, 36. The Kirby Institute, The University of New South Wales, Sydney.
- 2 Perkins, R., (1994). *Transgender lifestyles and HIV/AIDS risk*, AGPS, Canberra.
- 3 Couch, M., et al. (2007). *Tranznation: A report on the health and wellbeing of transgendered people in Australia and New Zealand*, Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.
- 4 Herbst, J., et al. (2008). Estimating HIV Prevalence and Risk Behaviours of Transgender Persons in the United States: A Systematic Review, *AIDS and Behaviour*, 12(1), 1–17.
- 5 San Francisco AIDS Foundation. (2009). *HIV Evidence Report: Transgender Persons and HIV*, 1. Retrieved from: <http://www.sfaf.org/policy-center/policy-library/sfaf-hiv-evidence-report-jan-2009-transgender-persons-and-hiv.pdf>
- 6 Personal communication, Ann McDonald, Kirby Institute, 20 January 2012.
- 7 See Herbst, J., et al. It is worth noting, however, that studies of transgender populations often don't include transgender men at all.
- 8 Alan, D., Gold, J., Gunnan, J. (1990). Transsexuality and HIV antibody seroprevalence: a study of risk factors, *Venereology*, 3, 100–102.
- 9 National Centre in HIV Epidemiology and Clinical Research (NCHECSR). (2010). *HIV, viral hepatitis and sexually transmissible infections in Australia: Annual Surveillance Report 2010*. NCHECSR, The University of New South Wales, Sydney, 4.
- 10 See Couch, et al., 30–37.
- 11 Reed, B., Rhodes, S., Schofield, P., et al. (2009). *Gender Variance in the UK: Prevalence, Incidence, Growth and Geographic Distribution*. Gender Identity Research and Education Society, Ashted.
- 12 Hounsfield, V., et al. (2007). Transgender people attending a Sydney sexual health service over a 16-year period, *Sexual Health*, 4(3), 189–193.
- 13 Hounsfield, et al., 191.
- 14 Perkins, R., op. cit., 34.
- 15 Perkins, R., op. cit., 42.
- 16 Perkins, R., op. cit., 34–42
- 17 Personal communication, Ann McDonald, Kirby Institute, 20 January 2012.
- 18 Not her real name. Interview: 23 January 2012.
- 19 Couch, et al., 33.

**Abigail Groves a former policy analyst at AFAO and a freelance writer.**



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# RETHINKING 'EQUALITY': THE GENDERED EXPERIENCE OF HIV RISK-TAKING AND PROSECUTIONS FOR HIV EXPOSURE AND TRANSMISSION

By Sally Cameron

Recent efforts to uncover gender analysis of HIV prosecutions have uncovered few examples of academic or policy based analysis. Here, Sally Cameron draws on her history in the HIV and women's sectors to raise some questions about the high proportion of women witnesses in Australian trials.

By the end of December 2011, 31 criminal prosecutions for HIV exposure or transmission are known to have occurred in Australia.<sup>1</sup> These 31 cases are diverse, making the building of a profile of the type of cases that proceed to court extremely challenging. Nevertheless, this task is essential if we are to unpack issues underlying HIV prosecutions so that affected communities may be informed about boundaries of behaviours that are not only safe but 'legal'.

To date, cases have included prosecutions for both HIV exposure and for transmission, cases where charges were dropped (5), cases that resulted in the accused being found 'not guilty' (11), and convictions where no defence was offered because the accused pled guilty, so evidence was not tested by the court (at least 9). Cases span HIV exposure/transmission to a single individual or

to multiple partner(s), during casual and committed relationships, and in new and long-term relationships. Some accused clearly lied about their HIV status or about using prophylactics, while in other instances the circumstances of the sexual relationships have been more difficult to determine. However, one factor has remained consistent: Australian prosecutions for HIV exposure and transmission are highly gendered.

## Common factors

### Men accused

All those charged with HIV exposure or transmissions have been men, except for a 1991 Victorian case involving a female sex worker.<sup>2</sup> Charges against both individuals were dropped immediately before trial; no other woman is known to have been charged since.

It may be tempting to attribute the overrepresentation of male accused to the fact that men comprise the vast majority of people living with HIV in Australia<sup>3</sup> and men's behaviour generally is more likely to be recognised as criminal<sup>4</sup>, or to bend to gendered stereotypes of men being more sexually active or less considerate of (sexual) partners. However, the reasons why some men and not others are charged in these cases are more complex. For a start, ethnicity/migration appears to be an intersecting factor, with migrant African men overrepresented among heterosexual male accused, including those charged with exposure only offences and those found 'not guilty' of HIV transmission.

### Women complainants

The profile of complainant witnesses in HIV criminal trials is in marked contrast to Australian HIV epidemiology. Anal sex between men continues to be the primary mode of HIV transmission (accounting for 86% of diagnoses of newly acquired HIV infection between 2006 and 2010<sup>5</sup>), yet HIV exposure/transmission cases are more likely to involve heterosexual sexual activity (see Figure 1, overleaf).

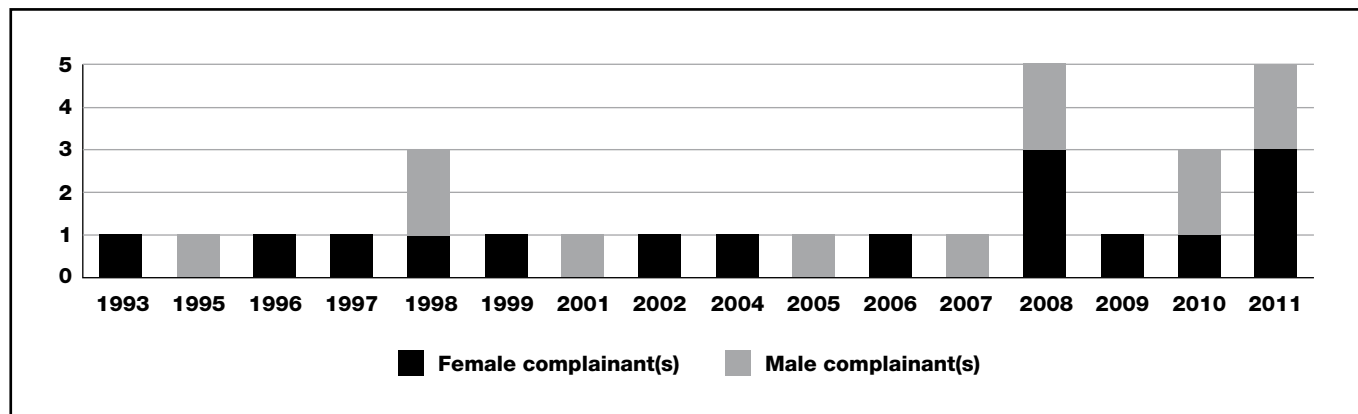
During the last decade (2002–2011), 63% of cases involved female complainant witnesses and only 37% involved male complainant witnesses (see Figure 2, overleaf).

The over-representation of women complainants suggests that irresponsible behaviour in heterosexual and gay/MSM relationships is differently understood by those directly involved and by those in the criminal justice system who may later scrutinise those behaviours. In 2009, the National Association of People Living With HIV/AIDS (NAPWA) criminalisation monograph posed the question:

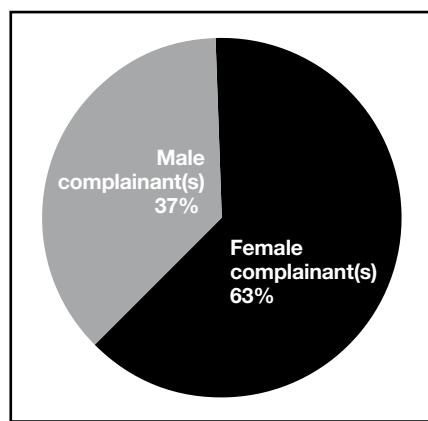
*'Why does criminal law treat HIV differently from other diseases? What social or cultural "filtering" of the "meaning" of HIV infection informs the decisions of complainants to complain, police to investigate, prosecution offices*

*continued overleaf*

**Figure 1** Australian prosecutions (of men) for HIV exposure or transmission



**Figure 2** Prosecutions: 2002 – end 2011



*to pursue, and judicial officers to hear these cases and not cases of other disease transmission?*

The same questions apply to the impact of gender on HIV and risk taking. Why does criminal law treat women’s exposure to HIV infection differently from men’s? And why are women more likely to perceive themselves as victims, to complain and/or to be taken seriously by actors in the criminal justice system? These questions sit at the intersection of the experience of gender in intimate heterosexual relationships and in criminal law.<sup>8</sup>

### Feminist jurisprudence

Gender bias in criminal law comes as little surprise, even if feminist legal experts of the 1980s and ‘90s were largely successful at arguing the inherent gender bias of the Australian

legal system, built as it is on male privilege over many hundreds of years. Frequently, feminist based law reform focused on abuses of power or violence exercised in intimate relations: a challenging area confronting not only gendered norms but also legal definitions of private life and the state’s right to intervene in private domains. At times, law reform has meant the rewriting of laws, such as the introduction of the law prohibiting (recognising) rape in marriage introduced in Queensland less than 25 years ago: the very notion of rape as a crime having evolved as a means to prevent damage to men’s ‘property’, i.e. their wives or daughters. At other times, law reform has involved police or administering justice agencies changing their interpretation of law, for example, using existing assault laws in cases of domestic violence rather than ignoring that violence by rationalising it as a man’s right to keep his wife in order.

Women’s experience of HIV infection sits uncomfortably amidst feminist legal analysis of harm to women occurring in intimate relationships. Such cases represent instances of women being harmed by their male sexual partners; however, it does not follow that such cases should become an issue to be determined by the courts. When should a betrayal of trust within an intimate relationship be considered criminal and when should it remain outside the purview of criminal law?

Should it be viewed as just another of the innumerable betrayals of trust that no doubt daily occur, including infection with diseases other than HIV, unwanted pregnancies, depression, financial distress, vitriolic custody disputes, lack of access to children and the ending of treasured relationships.

Matthew Weait has problematised the construction of HIV-related harm under criminal laws by arguing that ‘the way in which the “harm” of HIV is constructed and reproduced through law ... is no different from being beaten or poisoned ... yet is this the experience of infection?’<sup>11</sup>. This question is particularly relevant as it cuts across the importance of intent. In Australia, an instance of domestic violence resulting in physical injury may result in an order for the assailant to stop or to not go near the victim, without any criminal charges being laid. In other words, the law often recognises that violence within a personal relationship, committed with the intention and high likelihood of injury, is ‘wrong’ (it should stop), but it is not necessarily treated as ‘criminal’. However, failure to disclose HIV-positive status (without intention to harm) before a sexual act involving a low chance of injury (given the low risk of transmission associated with many acts) may be judged criminal. Moreover, we know that people routinely find HIV disclosure very difficult, and some people do not disclose before they commence

a sexual act – not because they want to overpower others (as in cases of sexual assault) but because they fear the consequences: i.e., the HIV-positive person (who becomes ‘the perpetrator’) will be harmed, including being rejected (by their new or long-term sexual partner) and information concerning their HIV-positive status being circulated.<sup>12</sup>

### **Intimate relationships**

In 1975, the Australian government made a radical change to Family Law, endeavouring to remove from the courtroom much of the personal misery experienced by those wishing to divorce. Prior to that date, getting a divorce had required one party to prove one of 14 grounds, including adultery, desertion, cruelty, habitual drunkenness, imprisonment or insanity. Proving those grounds often involved considerable expense and humiliation for one or both parties. The *Family Law Act 1975* introduced a single ground for divorce – being that the marriage has broken down irretrievably. The only requirement was (and remains) that a spouse shows they have been separated for 12 months – often little more than an administrative procedure of both spouses signing the prescribed form. While not an example from criminal law, the 1975 change to Family Law remains a persuasive example of a shift in thinking about the utility of laws and courts intervening in matters of harm causing relationship breakdown.

Intimate human relationships are complex, involving expectations, attachments and interdependencies. Even in the most fleeting of sexual encounters, issues of expectation and trust remain central. Yet, betrayals of trust within intimate relationships, including infidelity, are frequent; the consequences often dire, with intense human emotions aroused. Of course, criminal law is notoriously inept at dealing with the intricacies of interpersonal relationships (let alone ‘victims’) and technically, is focused on issues such as intent and harm,

yet the question of when betrayal becomes criminal remains central to the drafting of legislation and to its subjective administration.

### **Developing an Australian response**

Unfortunately, we have only limited information about most Australian HIV criminal cases as many prosecutions have been unreported or have been suppressed. Still, this article does not suggest that the women complainants involved in Australian trials have been overzealous or undeserving in seeking access to justice through the criminal courts. We know that some female complainants have been deliberately deceived, including accused deliberately scheduling medical appointments when their partner was at work, forging HIV test results, lying when asked directly about their HIV status, and removing condoms during sex. We are also aware of terrible consequences of accused’s behaviour including HIV infection of women now in poor health, of women solely responsible for the care of children, and the death of a child.

At the same time, it is difficult to understand why certain cases have proceeded to become long and expensive criminal trials – including the five prosecutions for exposure only and a case involving a woman infected by her boyfriend (who had not disclosed), whom she then married. We are also aware of ways in which trials have harmed the women involved, including that in which a woman complainant’s confidentiality was breached because although her name was suppressed, her husband’s (the accused) was reported.<sup>13</sup>

In 2009, the international ATHENA Network launched its ‘10 Reasons Why Criminalisation of HIV Exposure or Transmission Harms Women’<sup>14</sup>. Most of its arguments, while compelling when considered in African and other developing country contexts, have minimal application in Australia as they relate to communities where

women have very limited capacity to control their sexual and reproductive choices amid heterosexual HIV epidemics in resource-poor settings.

The Australian context is very different. The human rights-based public health framework has delivered impressive results both in terms of HIV prevention and positive people’s access to treatment and rights. Australia has an ‘alternative’ to criminal law intervention<sup>15</sup>: public health mechanisms in each state and territory to intervene in instances of individuals placing others at risk of HIV infection, with interventions ranging from education, counselling and support to detention. What then is our response to the gendered nature of criminal prosecutions? How can it be located within gendered patterns of intimate relationships? How easy is it for men to disclose HIV-positive status within heterosexual relationships, particularly prior to any sexual act occurring? How realistic is it to expect mainstream heterosexual Australia to uptake messages of shared responsibility for sexual health so diligently communicated to gay communities? For a start, where might they hear such messaging?

In the first instance, we need to know more about women’s experience of Australian HIV prosecutions and the reasons why these 16 cases, of the thousands of cases of HIV-negative women having sex with HIV-positive men, proceeded to trial. How do these cases fit within UNAIDS policy guidelines which argue that prosecutions should be limited to cases of intentional HIV transmission, i.e. where a person knows his or her HIV status, acts with the intention to transmit HIV, and does in fact transmit it.<sup>16</sup> The intention to have unprotected sex is not synonymous with an intention to transmit HIV, particularly given that a single sexual encounter includes a limited to remote risk of HIV transmission. Clearer guidelines for police and prosecutors,

*continued overleaf*

and communication between justice and HIV community sector organisations, are required.

Australia's response to HIV depends on an enabling environment which aims to limit stigma and discrimination, uphold human rights, and provide effective treatment for people living with HIV: the same people who fought both to position themselves as whole people – not victims (rejecting the patronising misrepresentation of the 'HIV sufferer' tag), and against binary definitions of worth (the 'innocent'/undeserving being children and those with medically acquired HIV, and those 'guilty' /deserving' being gay/sexually active/drug using).

Individual criminal cases involve women who have been deceived and sometimes physically harmed as a result of HIV infection. Still, the overrepresentation of women complainants is unsettling. 'Women's empowerment' encouraged women to exercise their legal rights: to eschew the role of victim generally by insisting that the legal system recognise their unacceptable victimisation, the victimisation of an equal and entitled person, in a particular instance. That argument is problematic. Is it possible to position oneself/or be positioned as 'victim' in a particular context and point in time (the trial) or does 'victimhood' have a more complex temporal evolution/resolution?<sup>17</sup> What if the end result of arguments for legal equality is more women representing themselves (or being pushed to participate in trials) as 'victim' in this context? Will that encourage other women to do the same, and will

women living with HIV be increasingly positioned as 'victim of HIV man' – further disempowering women, stigmatising women living with HIV and undermining Australia's public health response?

## References

- 1 That number represents cases ranging from those where individuals were charged but the case dropped pre-trial, to those where full trials were held. Anecdotally, it is known that others have been investigated without formal charges being laid – that information coming from informants including both those previously investigated and health department staff.
- 2 A male sex worker was also charged, suggesting 'occupation' is at least a likely a reason for the state's interest as gender. These two cases are the first known cases of Australian criminal laws being used to prosecute HIV exposure/transmission.
- 3 Estimated at 19,407 males and 1,984 females during 2011. The Kirby Institute. (2011). *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2011*. The Kirby Institute, the University of New South Wales, Sydney.
- 4 At June 2009, there were almost 30,000 adults in Australian prisons (175 prisoners/100,000 adult population), with men imprisoned at 13 times the rate of women. While imprisonment rates are not a direct reflection of levels of crime they clearly reflect those convicted of crimes for which jail terms are deemed an appropriate punishment. Australian Bureau of Statistics (ABS). (2009). *Prisoners in Australia, 2009*. (cat. no. 4517.0). Retrieved from: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4517.02009?OpenDocument>
- 5 The Kirby Institute, op. cit.
- 6 Those figures reflect percentage of cases not percentage of complainants, as some cases involve multiple complainant witnesses. Reviewing all cases back to 1991 where the gender of the alleged 'victim' is known (all but 4) reveals strikingly similar statistics: 67% of cases involved female complainant witnesses and only 33% involved male complainant witnesses.
- 7 Cameron, S., Rule, J. (2009). Outside the HIV strategy: challenges of 'locating' Australian prosecutions for HIV exposure and transmission in Sally Cameron and John Rule (eds). (2009). National Association of People Living with HIV/AIDS (NAPWA). *The Criminalisation of HIV Transmission in Australia: Legality, Morality, and Reality*. NAPWA, Sydney, 18.
- 8 These questions do not ignore the reality that gendered experience of HIV risk is informed by issues of sexuality/homophobia, Australia's HIV education focus on populations engaging in high risk acts and consequent uptake of shared responsibility messages but argues these questions have not been closely explored with women/heterosexual sex as the focus.
- 9 Given our reliance on English law.
- 10 Which stands out in my mind as it occurred in July 1989, the month I was employed at Queensland's Women's Legal Service. Prior to that, the 'crime' did not exist so a husband could not be charged.
- 11 Weait, M. (2007). *Intimacy and Responsibility: The Criminalisation of HIV Transmission*. Routledge-Cavendish, London and New York, 110.
- 12 See, for example, Grierson, J., Power, J., Pitts, M., et al.(2009) *HIV Futures 6: Making Positive Lives Count*. The Australian Research Centre in Sex, Health and Society, Latrobe University, Melbourne; and Reader contributions (various). (2011). *Everyday Life: Disclosure. Talkabout, 175*. Positive Life NSW, Sydney. Retrieved from: <http://positivelife.org.au/talkabout-gets-animated>
- 13 Our colleague from New Zealand continues to be approached by journalists, despite being a complainant witness in a trial almost years ago.
- 14 ATHENA Network. (2009). *10 Reasons Why Criminalisation of HIV Exposure or Transmission Harms Women*. Retrieved from: <http://www.aln.org.za/downloads/10ReasonsWhyCriminalisationHarmsWomen.pdf>
- 15 Recognising public health interventions are not formal 'alternatives' but arguably operate to address behaviours that may otherwise become the subject of criminal complaint.
- 16 Joint United Nations Programme on HIV/AIDS (UNAIDS and United Nations Development Program (UNDP). *UNAIDS/UNDP Policy Brief: Criminalization of HIV transmission*, UNAIDS. Geneva, 2008.
- 17 Academics such as Wendy Brown have argued that relying on the state to recognise and punish injury effectively attaches the identity of injury to the injured party, and at macro level perpetuates notions of the need for state protection: 'the heavy price of institutionalized protection is always a measure of dependence and agreement to abide by the protector's rules'. See Brown, W. (1995). *States of injury: power and freedom in late modernity*. Princeton University Press, Princeton.

Australia's response to HIV depends on an enabling environment which aims to limit stigma and discrimination, uphold human rights, and provide effective treatment for people living with HIV

Sally Cameron is a consultant and former policy analyst at AFAO.



# THE HON. KAY HULL, MP: A CHAMPION FOR THE PARTNERSHIP RESPONSE TO HIV



The Hon. Kay Hull MP, Former National Party Representative for Riverina. Kay Hull entered the House of Representatives October 1998 and retired August 2010. Photo: AUSPIC.

Throughout her career, the now retired Hon. Kay Kull, MP has remained a consistent advocate for responses to HIV that directly involve affected communities. Kay is a former National Party Representative for Riverina and was Deputy Chair of the Parliamentary Liaison Group for HIV/AIDS, Blood Borne Viruses and Sexually Transmissible Infections. Over the years, Kay has also been highly involved in the development of many of Australia's National Strategies for HIV and STIs. What follows is a brief tribute to her efforts to further the Australian partnership response to HIV.

**By Graham Brown,  
AFAO President (2008–2011)**

Kay Hull has been advocate for the Australian response to HIV – and for people living with and affected by HIV – for many years. Her commitment to HIV and her bi-partisan approach to the Australian response extends far beyond her involvement with the Parliamentary Liaison Group for HIV/AIDS Blood Borne Viruses and STIs.

Kay was appointed to the Inter-Parliamentary Union advisory group on HIV/AIDS, and participated in numerous United Nations High-Level Meetings on HIV/AIDS. These, and other events, firmed Kay's resolve to restore Australia's leadership regarding HIV. In a motion to the House of Representatives back in 2008, pressuring for the development of a new HIV strategy, Kay argued that 'we are heavy on rhetoric and principles but we are most definitely lacking leadership and drive in the delivery on the ground of a real HIV strategy' – a call that was being echoed through the community sector.

Subsequently, Kay became one of the many advocates participating in the development of the National HIV and STI Strategies. She was always willing to speak out about the need to reinstate community involvement and the involvement of people living with HIV in the development and delivery of the National HIV Strategy – and was a critic of rhetoric that lacked substance. From her passionate stance on reducing stigma and discrimination and publically aligning herself with the fight against criminalisation of HIV, to arguing the need for increased and targeted resources for prevention, many of Kay's achievements are on the public record. However, many of her largest achievements were completed through her behind the scenes advocacy; although less visible, their impact was keenly felt.

*continued overleaf*

I am grateful to have had Kay on our side through many of the policy and political challenges over the years – both in Australia and internationally – drawing on her passion, talent, and personal commitment for advocacy in HIV and her ability to make things happen. Thank you Kay.

**By Senator the Hon. Louise Pratt, Senator for Kalgoorlie, WA and Chair of the Parliamentary Liaison Group for HIV/AIDS, Blood Borne Viruses and STIs**

Kay embodies the qualities people want in a representative – compassion and courage backed up by strong and practical commitment.

We are fortunate that Kay has devoted so much of her personal and political talent and passion over very many years to addressing HIV/AIDS. Her great advocacy saw her appointed to the International Parliamentary Union's (IPU) HIV/AIDS Advisory Group, at the request from the Secretary-General of the IPU, who recognised her commitment to people living with HIV.

I am honoured to have worked with Kay in the Parliamentary Liaison Group for HIV/AIDS Blood Borne Viruses and STIs. The importance of a bi-partisan commitment to addressing HIV/AIDS has been a fundamental lynch pin to a successful response to HIV here in Australia. Without champions like Kay working with affected communities, we know that the response to HIV would have been one of fear and discrimination.

As the Member for Riverina, a rural National Party electorate, Kay played a vital role in educating people from all



**Pictured L-R:** The Hon. Kay Hull MP, Robert Mitchell (NAPWA President), Senator Louise Pratt (Senator for Western Australia) at the launch of the NAPWA criminalisation monograph, Parliament House, Canberra (2009). The resource was officially launched by Kay Hull MP in her capacity as Deputy Chair of the Parliamentary Liaison Group for HIV/AIDS and Senator Louise Pratt as Chair of the Parliamentary Liaison Group for HIV/AIDS, BBVs and STIs.

walks of life about HIV. Kay worked hard with PLWHA to destroy stigma and stereotypes and importantly, to campaign for access to treatment and trained healthcare professionals.

This not only included better access for people with HIV in regional and rural Australia but importantly, internationally – for the millions of people around the world who need treatment.

Kay was a global advocate, arguing in Parliament with passion for greater 'investment in workforce availability across the world to enable the delivery of antiretroviral therapies to those who are affected. It is a fact that many

developed countries are poaching trained professionals from developing countries, and we are sadly leaving these areas with no ability to treat this HIV/AIDS epidemic,' she said.

Kay argued for strong prevention measures – this meant that she could be counted on to support targeted prevention campaigns for at risk communities and combat discrimination and stigma.

What I most admire about Kay was her ability to bridge the city/country divide in tackling issues of HIV. Her advocacy was a potent reminder that HIV doesn't care about where you live, your race, gender or sexuality – it affects people from all walks of life.

Kay, I miss you in our parliamentary work. I know that your passion and commitment to addressing HIV will extend beyond your many years in parliament.

Thank you Kay.

Kay was a global advocate, arguing in Parliament with passion for greater 'investment in workforce availability across the world to enable the delivery of antiretroviral therapies to those who are affected.'



**BOOK REVIEW: 100 DOLLS,  
COUNTLESS HEARTS –  
STORIES OF CHILDHOOD FROM  
MULTICULTURAL AUSTRALIA  
FOR THE UTHANDO PROJECT**  
Published by Uthando Project Inc.  
2012

The tradition of making handicrafts to benefit community has a long history. Since at least World War I, when they knitted socks and balaclavas for soldiers on the cold European fronts, Australian grandmas, mums, sisters – and occasionally dads and brothers – have sewn, knitted, crocheted and quilted for a variety of altruistic purposes. *100 Dolls, Countless Hearts* documents the creative reinvention of this grand old tradition through the Uthando Project, an organisation and grassroots movement started by Georgia Efford in Western Australia.

The Uthando Project coordinates doll-making workshops throughout Australia, as well as in South Africa. The dolls are made by school children, retired and refugee women, and HIV-positive women, among many others. The dolls are given to HIV-affected children in KwaZulu Natal province in South Africa, where they are used to help them recover from trauma, loss and grief, using imaginative play.

Uthando's South African partner organisations<sup>1</sup> use the dolls to work with children and their families in a variety of ways, such as in training workshops for community workers; family support workshops aimed at strengthening adult's relationships with their children and grandchildren; and programs supporting HIV-positive mothers to disclose to their children.

*100 Dolls, Countless Hearts* documents the stories of the doll-makers, the work of Uthando's program partners, and also discusses the African HIV pandemic and its effects on children. Photographs feature prominently throughout; every page is a feast of colour as the dollmakers or the new doll owners pose with their dolls – each one a unique work of textile art.

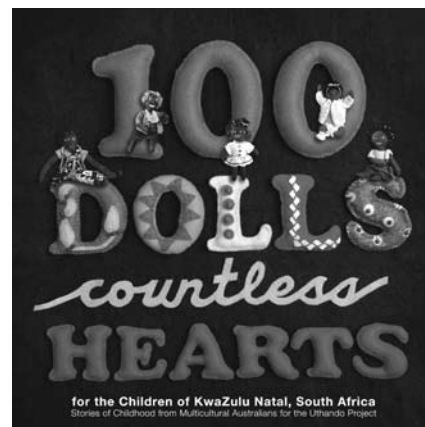
The doll-makers speak of their own childhoods – their toys and games, their families and relationships, their hardships and inspirations, and their thoughts about the dolls they have made and the process of making them.

Says Bev, born in Perth in 1936: 'I hope this doll will make a little boy in Africa's life just a little bit better. I hope he will feel the love with which it was made and it will be not just a toy but a friend to him.' (p. 28)

Laurel, an Indigenous woman, says, 'Making this doll feels so nice – to be with everybody – and it takes me back to my own childhood'. (p. 51)

Bienfait, a Community Educator, took part in a 'Doll-making for Community Leaders' workshop, held in Perth. Hosted by the WA AIDS Council and the Metropolitan Resource Centre, the workshop used doll-making as a tool to help break down 'complex cultural and social barriers' that can prevent open communication around sensitive topics such as HIV and sexual health. Bienfait explains: 'What it meant for me is that I can ... talk easily to people about HIV/AIDS through doll-making'. (p. 187).

Carol Mitchell and Megan Greer from the Sizabantwana (Helping Children) project in Kwazulu Natal describe how both boys and girls in their region have an 'immense and overwhelming' need for the dolls. Playing with the dolls helps the children express and process painful emotions, giving project workers the opportunity to identify their needs and take action to assist them (p. 32–33). It struck me that in a country where sexual violence has been



The cover of *100 Dolls, Countless Hearts* – designed by Natalija Brunovs

a significant driver of the epidemic, a project that helps young boys with emotional healing is sure to have multiple benefits reaching far into the future.

Delightful as this book is, it's not just a coffee table book with a conscience. The publishers encourage readers to adapt Uthando's principles to suit their own needs and contexts. Accordingly, the book also contains patterns and instructions for crafting a variety of cloth and knitted dolls, doll's clothes, accessories, hand puppets and African animals. It's time to get knitting!

**Proceeds from sales of *100 Dolls, Countless Hearts* will go to support Uthando partner Dlananathi, a South African NGO whose mission is to 'bring hope and healing to children, families and communities' though supporting child-raising and family relationships. You can order copies of the book, as well as find out more about the project at <http://www.uthandoproject.org>**

## Reference

- 1 Africa Centre for Health and Population Studies; Lifeline and Rape Crisis, Sizabantwana; Tree (Training and resources in Early Education); and Dlananathi.





## WEB WATCH:

<http://www.genderandaids.org>  
**UN Women – gender equality and HIV/AIDS – web portal for gender equality dimensions of the HIV/AIDS epidemic**

In June 2011, the United Nations (UN) commenced a reform agenda, in consultation with member-states, to increase the effectiveness and performance of its operations.<sup>1</sup>

As part of this process, it announced the formation of UN Women, an organisation dedicated to advocating for the rights of women and girls and highlighting gender inequalities worldwide.

Specifically, UN Women focuses on issues for women, including: preventing violence fostering leadership and participation, encouraging economic empowerment, and supporting the millennium development goals, including preventing the spread of HIV.

As part of this work, UN Women maintains a web portal dedicated to promoting issues related to the HIV pandemic as it affects women. The site – <http://www.genderandaids.org> – describes itself as a ‘comprehensive web portal of gender equality dimensions of the HIV epidemic’. The site provides access to stories, links, news, and participation opportunities through six main menus on the homepage.

The ‘resources’ section includes contributions from international women’s organisations, advocacy bodies, health organisations and activists, among many others. The content is diverse and includes CD-roms, data-sheets, factsheets, posters,

training materials and tool kits, as well multimedia content (video, films and photos). Users can browse resources by topic, subject or region. Topic areas include: adolescence and youth, legislation and policy, stigma and discrimination, prevention, and information for women living with HIV, just to name a few.

A nice feature of the resources section is that it clearly shows the number of documents available within each category and the year each document was produced, making the task of drilling down to find specific research very easy. At press time, the site presented 31 articles from African countries, 13 from Asia and the Pacific, five from Eastern Europe, eight from Latin America and the Caribbean, and three from Arab states.

The ‘Women’s story’ section of the site includes recent contributions about HIV-positive women in Guyana and ‘blogging positively: young women living with HIV speak out’ – a sub-site of the ‘Rising Voices’ project, which showcases fantastic user-generated content from around the world. In just a few clicks I came across a fascinating article about citizen journalism produced by indigenous communities from the Northern Territory in Australia (including video content shot on a mobile phone in January 2012) as well as other case studies of HIV-related ‘citizen media’, with content available in English, Russian, Swahili, French and Spanish. An interesting feature of the ‘stories’ section is that it includes the number of hits for each item, so you can gauge what has been popular with other visitors to the site. The project “‘I am ...’ women living with HIV” ranked top, with over 2,500 visitors.

The content of the news section included articles on ‘Gender issues in the Caribbean’, a recent US study regarding cervical cancer and young HIV-positive women, and analysis of the links between HIV and poverty as

it affects women and girls in Indonesia. Curiously, there were only two news items posted in 2011, but by clicking other links throughout the site, I was able to access other recent news items of interest; I was unsure by what criteria UN Women decides to feature news items directly on its site.

The site provides links to a cross-section of organisations and information providers, including media sites (6), non-government organisations (NGOs), foundations and civil society organisations (17), academic research and training organisations (5), and resource sites and clearing houses.

An increased focus on South-East Asia and the Pacific would be desirable; for instance the site offered only 13 resources from these regions, and the most recent of these was from Vietnam (2011), with the next most recent being from 2008. At press time, there were no resources or news items on South-East Asia, the Pacific or Australia, although links from the site did lead me to information from these regions. I also wondered about how frequently site information was updated. For instance, the lead story under ‘latest news’ was about ICASA conference ‘being held this week’, two months after the event had passed. Also, ‘upcoming events’ only listed one item, the international AIDS conference – surely there are other HIV/AIDS Conferences that UNAIDS is aware of?

Nevertheless, I found the site engaging, stimulating and easy to use. I enjoyed surfing around and quickly discovered lots of great international content – so, my few misgivings aside, the site lives up to its aims of being a portal to diverse information about women and HIV.

## Reference

- 1 Ban appoints experienced UN official to lead change management team. Retrieved from: <http://www.un.org/apps/news/story.asp?NewsID=38563&Cr=khare&Cr1=>

BY FINN O’KEEFE, COMMUNICATIONS OFFICER AT AFAO



## TREATMENT BRIEFS

### NEW BHIVA GUIDELINES RECOMMEND DISCUSSION WITH ALL PATIENTS ON POTENTIAL OF HIV TREATMENT TO PROTECT SEXUAL PARTNERS

The British HIV Association (BHIVA) has announced a recommendation that doctors should discuss the evidence for the effectiveness of antiretroviral treatment as prevention with all patients with HIV, and that antiretroviral medication should be offered to all HIV-positive people who want to protect their partners from the risk of HIV infection – even if they have no immediate clinical need for treatment themselves.

The guidelines stipulate that all patients should be informed of this evidence, but no patient should be forced to take treatment for this reason.

The recommendation forms part of new adult antiretroviral treatment guidelines for the United Kingdom – issued for consultation this week.

Although BHIVA continues to recommend that people start treatment at a CD4 cell count of 350 or below, the guidelines also recommend that doctors should discuss the evidence that treatment reduces the risk of HIV transmission to partners with patients who have CD4 counts above 350. If patients want to start treatment to reduce the risk of transmitting HIV to a partner they should be allowed to do so.

Evidence from a large trial of the effects of earlier antiretroviral treatment on HIV transmission to partners has convinced UK doctors that treatment

should be offered in circumstances where patients are concerned about the risk of transmitting HIV to partners – even if they are not in a serodiscordant relationship at the time.

Patients should also be told that the evidence of a lower risk of transmission on treatment mainly relates to vaginal sex, not anal sex, and that use of condoms will continue to protect against sexually transmitted infections as well as lowering any residual risk of HIV transmission.

**Further information on the BHIVA Guidelines is available at [www.bhiva.org](http://www.bhiva.org)**

— Keith Alcorn (Aidsmap)  
Published: 6 February 2012

### TENOFOVIR ASSOCIATED WITH INCREASED RISK OF KIDNEY DISEASE

Treatment with tenofovir is associated with a modestly increased risk of three key markers of kidney disease, US investigators report in the online edition of *AIDS*.

The large study involved over 10,000 patients who started antiretroviral therapy between 1997 and 2007.

Patients treated with tenofovir were significantly more likely to develop proteinuria (high levels of protein in urine), experience a rapid decline in kidney function and have chronic kidney disease (an estimated glomerular filtration rate below 60 ml/min/1.73 m<sup>3</sup>.<sup>1</sup> The risk of kidney disease also remained elevated for patients who discontinued tenofovir therapy.

‘Even after accounting for demographics, HIV-related factors, comorbidities, and other antiretroviral drugs, tenofovir remained associated with an increased risk for each kidney disease outcome,’ write the investigators.

The authors stress the drug’s association with proteinuria and CKD, noting ‘each is independently associated

with cardiovascular disease and death in the setting of HIV infection.’ However, they also emphasise the importance of tenofovir in HIV treatment and that the risk of kidney disease associated with the drug should be balanced against its potential benefits. Moreover, the authors do not regard their research as definitive and call for further research.

Patients with HIV have an increased risk of kidney disease. The exact causes are controversial, but appear to include the effects of HIV itself, traditional risk factors such as hypertension and diabetes, co-infection with hepatitis C, and possibly the side-effects of some antiretroviral drugs.

The research exploring the association of tenofovir (*Viread*, also available in the combination pills *Truvada* and *Atripla*) with kidney disease is contradictory. Although some studies found an association between the drug and kidney dysfunction, this was not the case with others.

Differences in patient populations, limited sample sizes and lack of access to the appropriate laboratory data could be the reason for the lack of concordance between studies.

It is important to establish if the drug does increase the risk of kidney disease. Tenofovir is widely used in first-line antiretroviral therapy and also has an important role in pre-exposure prophylaxis (PrEP) regimens. Moreover, kidney dysfunction is a risk factor for cardiovascular disease, which is an increasingly important cause of illness and death in patients with HIV.

Therefore, investigators from the US Department of Veterans Affairs designed a study to determine the effects of tenofovir exposure on the risk of kidney disease.

*continued overleaf*



Their study population comprised 10,841 patients who started antiretroviral therapy for the first time over a ten-year period between 1997 and 2007. A total of 4,303 individuals were exposed to tenofovir. There was no difference between the tenofovir-treated patients and the patients treated with alternative antiretroviral drugs in terms of the prevalence of diabetes and hypertension, hepatitis C co-infection, CD4 cell count and viral load. Prevalence of proteinuria at baseline was comparable between the two groups of patients.

The overall mean age was 46 years and 98% of individuals were men. Mean duration of tenofovir therapy was 1.3 years. The investigators acknowledge that this short period of treatment was a limitation of their study. The study did not report on the absolute risk of kidney disease.

In all the investigators' models, both any use of tenofovir and cumulative exposure to the drug was strongly associated with a significant increase in the risk of all three markers of kidney disease ( $p=0.0033$  to  $p<0.0001$ ).

Therapy with tenofovir was also associated with the presence of both proteinuria and CKD ( $p=0.0014$ ), a more stringent measure of kidney disease. 'The effects of tenofovir on kidney disease risk were not reversible following discontinuation,' comment the authors.

However the presence of other risk factors for kidney disease did not increase the risk of kidney disease while taking tenofovir; indeed, the association between tenofovir treatment and kidney disease was significantly weaker in older people, diabetics and people with cardiovascular disease or hypertension when compared to younger people or those without these conditions.

Tenofovir was the only anti-HIV drug with significant associations for all three measures of kidney disease used in the study. Nevertheless, several other drugs increased the risk of individual measures

of renal dysfunction. For instance, ritonavir (*Norvir*) increased the risk of proteinuria ( $p<0.0001$ ). Atazanavir (*Reyataz*) was associated with a rapid decline in kidney function ( $p=0.0035$ ), and abacavir (*Ziagen*, also in the combination pills *Kivexa* and *Trizivir*) had a significant association with CKD ( $p=0.0019$ ).

The authors were well aware of the apparent significance of their findings and their potential to cause alarm among patients. They therefore believe it is important to balance the benefits and risks of therapy with the drug.

'Despite tenofovir's association with progressive kidney disease, it is an important component of effective antiretroviral therapy that may be required in many patients to control viral load,' conclude the investigators. 'The balance between its efficacy and probably adverse events requires further study.'

## Reference

- 1 Scherzer, R., et al. (2012). Association of tenofovir exposure with kidney disease risk in HIV infection. *AIDS*, online edition. DOI: 10.1097/QAD.0b013e328351f68f, 2012

— Michael Carter (Aidsmap)  
Published: 13 February 2012

## US CDC RECOMMENDS HPV VACCINE FOR YOUNG MEN

Young men and adolescent boys between the ages of 11 and 21 should be vaccinated against human papillomavirus – the cause of genital warts, anal and cervical cancer – the Advisory Committee on Immunization Practices has recommended, in a new *Adult Immunization Schedule* published in *Annals of Internal Medicine*.

The US committee also recommended that all gay and bisexual men and HIV-positive men aged 26 and under should be vaccinated. Current US guidelines already recommend that young women and girls aged 11 to 26 should receive the vaccination.

In Australia, the National HPV Vaccination Program provides the HPV vaccine for all females through

school programs at age 12–13 years. This program is funded by the Commonwealth government under the Immunise Australia Program.

In the United Kingdom, HPV vaccination is offered to girls aged 12 and 13 through a National Health Service vaccination programme, although girls in the 14–17 age group can also be vaccinated.

Vaccination has been shown to reduce the subsequent risk of genital warts, pre-cancerous cervical changes and cervical cancer in women. In young men, the vaccine has been shown to reduce the risk of HPV infection.

In an accompanying editorial, Dr Sandra Fryhofer of Emory University, Atlanta, notes that although clinical data are not available, the rationale that vaccination also protects against oropharyngeal cancers caused by HPV is 'certainly plausible'.

A recent review of the impact of HPV vaccination in Melbourne, Australia, found that the risk of young men and women under 21 being diagnosed with genital warts fell by approximately 60% between 2007/08 and 2010/11 among patients attending the Melbourne Sexual Health Centre. This followed the implementation of a vaccination program in girls and women aged 26 and under from 2007 onwards.

The number of sexual partners did not affect the reduction in risk.

## References

- Advisory Committee on Immunization Practices. (2012). Recommended Adult Immunization Schedule: United States. *Ann Intern Med*, 156(3), 211–17.
- Fryhofer, S. (2012). Adult immunization 2012: Politics, process and progress. *Ann Intern Med*, 156(3), 243–5.
- Read, T., et al. (2011). The near disappearance of genital warts in young women 4 years after commencing a national human papillomavirus (HPV) vaccination programme. *Sex Transm Infect*, 87, 544–47.

— Keith Alcorn (Aidsmap)  
Published: 6 February 2012

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5–8  
**CROI 2012: 19th Conference on Retroviruses and Opportunistic Infections**  
<http://retroconference.org/2012>

21–23  
**10th European Meeting on HIV and Hepatitis: Treatment Strategies and Antiviral Drug Resistance**  
Barcelona, Spain  
<http://www.virology-education.com>

### ● **April**

1–3  
**Sex::Tech 2012: Conference on Youth, Technology and STD/HIV Prevention**  
San Francisco, United States  
<http://sextech.org>

12–13  
**Silence & articulation: the 12th Social Research Conference on HIV, Hepatitis C and Related Diseases 2012**  
Sydney, Australia  
<http://nchsrconference2012.arts.unsw.edu.au>

15–18  
**M2012: International Microbicides Conference**  
Sydney, Australia  
<http://microbicides2012.org>

### ● **May**

8–11  
**6th INTEREST Workshop**  
Mombasa, Kenya  
<http://www.virology-education.com>

23–25  
**2012 ISHEID: International Symposium on HIV & Emerging Infectious Diseases**  
Marseille, France  
<http://www.isheid.com>

28–31  
**AFAO Gay Men's HIV Health Promotion Conference**  
Sydney, Australia  
<http://www.afao.org.au/events/hiv-educators-conference>

### ● **July**

20–21  
**Global Scientific Strategy towards an HIV Cure (working group)**  
Washington DC, United States  
<http://www.aids2012.org>

22–27  
**AIDS 2012 – XIX International AIDS Conference**  
Washington DC, United States  
<http://www.aids2012.org>

### ● **October**

15–17  
**13th IUSTI World Congress incorporating the Australasian Sexual Health Conference**  
[www.iusti2012.com](http://www.iusti2012.com)

17–19  
**Australasian HIV/AIDS Conference 2012 (24th Annual Conference of the Australasian Society for HIV Medicine)**  
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