

# HIV AUSTRALIA



## AIDS 2014 SPECIAL EDITION

# HIV and the enabling environment: Australia and our region

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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

Welcome to this special edition of *HIV Australia*, published to coincide with the 20th International AIDS Conference (AIDS 2014) in Melbourne, Australia.

2014 marks the first time that an International AIDS Conference (IAC) has been held in Australia, and ten years since the IAC was held in the Asia-Pacific region. Last year's ICAAP11 conference in Bangkok saw the international HIV community focus in on our region. This edition sharpens that focus – profiling community-led responses in Australia and the region, at a time when we are witnessing important new scientific developments and understandings about HIV.

This special edition is themed around HIV and the enabling environment. The strong framework of policies and laws that exist in Australia has underpinned the success of our much-lauded partnership response to HIV, involving community, clinicians, researchers and government, since the beginning of Australia's HIV epidemic. The edition includes analysis of the current state of Australia's policy framework, identifying laws that undermine the enabling legal environment.

Several articles in this edition trace the history of Australia's HIV response – from 'medical emergency', prompting strong community activism, to an era of focusing on treatment uptake and increasing testing rates. Contributors ponder the fact that as people with HIV live with a chronic manageable disease, an urgency about the HIV response has stalled, highlighting a need to focus on enabling social and legal environments to address ongoing stigma and discrimination.

Other contributors outline innovative work across Asia and the Pacific, where community organisations and networks operate in social and political environments that are, in many cases, far from enabling. We hear how the rights of people living with HIV, and communities most affected by HIV are severely impinged, undermining access to health services, HIV testing, treatment, care and support – or to simply the right to live free from persecution.

A number of articles in this edition discuss cross-country partnerships and capacity building initiatives that are strengthening community responses to HIV, nurturing emerging community leaders, and taking a successful 'learning by doing' approach in combating HIV.

This year's IAC conference in Australia will see some important milestones, including a conference program that has been driven by the involvement of people living with HIV and key affected communities at every level, and the first ever keynote address delivered by an Indigenous person.

This special edition of *HIV Australia* is designed to provide a snapshot of the energy, action and innovation that exists within Australia, Asia and the Pacific. We encourage readers to network and start conversations with the people and organisations driving the work you will read about within these pages.

The AIDS 2014 edition of *HIV Australia* will be formally launched on Wednesday 23 July at 5.15pm in the G'day! Welcome to Australia Networking Zone in the AIDS 2014 Global Village. Visit the G'Day! Zone to learn more about the Australian HIV response, or just to relax and network. We look forward to seeing you there!

**Finn O'Keefe and Linda Forbes**

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*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)

# Hopes for AIDS 2014 and beyond

By **Professor Sharon Lewin**

It is fitting in many ways, that after three decades of the HIV epidemic, the International AIDS Conference is finally coming to Australia. Fitting because Australia has punched way above its weight on a global level in response to HIV – from the very beginning.

There's much to admire in Australia's well documented response to HIV: its bipartisan political approach to the disease has undoubtedly been a major driver in Australia having one of the lowest rates of HIV infection worldwide. The inclusion of key affected communities – sex workers, gay men, and people who inject drugs – as equal partners in the response from the outset has been fundamental in an effective response. And lastly, the capacity building in science and research around the epidemic has played a pivotal role in driving evidence-based public health policy, innovation and access to the latest treatments and prevention strategies for affected communities.

As a scientist I am enormously proud of what Australian science has contributed in the fight against the epidemic and I am thrilled about where it is going, too.

For near on two decades now we've been guided by the annual surveillance reports provided by the Kirby Institute (formerly known as the National Centre in HIV Epidemiology and Clinical Research), led by Professor David Cooper, previous President of the International AIDS Society. Professor Cooper has been a giant opinion leader in international forums. The Kirby Institute's new home on campus at the University of New South Wales will be officially launched the week before AIDS 2014, and is set to further expand its influence beyond HIV into the broader brief of 'infection and immunity in society'.

The Centre for Social Research in Health and the Australian Research Centre in

Sex, Health and Society continue to inform us on how best to address harm in sexual and drug use behaviours – so vital to getting the evidence to develop and implement new prevention and treatment strategies and to deliver the most effective messages as part of broader education campaigns.

The Australian Centre for HIV and Hepatitis Virology Research has diversified from a focus on basic virology to using translational science to find new diagnostics, new antivirals, and to accelerate the path to find effective vaccines for HIV, hepatitis B and hepatitis C. Australian innovations such as a bedside CD4 test could soon transform HIV management in low income countries.

And of course the work of Melbourne's Burnet Institute since the early 80s, whether in or out of the lab, or around harm reduction, malaria or HIV, has without doubt made a huge contribution to global health and, closer to home, played a key role in helping to guide responses to the HIV epidemic in the Asia and Pacific regions.

The launch of the Peter Doherty Institute for Infection and Immunity at the University of Melbourne as a leading infectious diseases research centre is also an exciting development, and one I'll be very proud to lead over the coming years.

Yes, these are exciting times for Australian HIV science; indeed HIV science is riding a renewed sense of optimism globally.

The response to the HIV epidemic over the past three decades has been a monumental achievement in global health, both scientifically and logistically. In less than three decades, the discovery of effective antiretroviral therapy (ART) has transformed HIV infection from an inevitable death sentence to a chronically manageable disease. This has been one

of the past century's greatest human achievements in health, and getting 11 million people on ART in low and middle income countries in just over a decade has been a massive task.

Universal access to these life-saving medicines must remain a priority – particularly given we now know that antiretrovirals not only save lives but also reduce transmission of the virus.

Pre-exposure prophylaxis (PrEP) is also now a part of the equation, and the revitalised interest in HIV cure research has gained strong momentum since the first man cured of HIV, Timothy Brown, was reported in 2009. Recent reports of HIV functional cure following very early initiation of ART – such as the Mississippi baby and the VISCONTI Cohort – have given scientists great hope that a cure is indeed possible. The discovery that some patients produce very effective antibodies has also recently raised hopes for new directions in vaccine research. It is clear that science will continue to deliver.

But as the Australian experience has shown, science alone is not enough to carry an effective response to HIV – it must be accompanied by a combination of community engagement and political leadership, and unfortunately both have been in short supply in too many countries. In many parts of the world, stigma and discrimination fuelled by unacceptable government policies, cruelly prevent millions of people from accessing treatment, care and prevention, and ultimately prevent us working towards the end of the epidemic.

With 2.3 million new infections and more than 1.5 million deaths reported globally in 2012<sup>1</sup>, we simply cannot say that HIV is under control. Only 34 percent of people eligible for treatment worldwide are receiving antiretrovirals.<sup>2</sup>

Progress, as welcome as it is, is still fragile and many challenges remain, the

greatest of which is implementing the science that we know works.

AIDS 2014 comes at a pivotal time in the epidemic: the Millennium Development Goals come to fruition next year and already there is much discussion on what a post-2015 global health scenario will look like and where HIV/AIDS will sit in that brave new world.

It is my strong belief that besides showcasing some exciting new science around hepatitis and TB co-infection, HIV paediatrics, PrEP and cure research, the AIDS 2014 conference will allow Australia and the rest of the world to reflect on and consider some of the controversial retreats being made in many country responses to the epidemic. We need to reverse the dwindling political and financial support for proven, cost-effective harm reduction interventions.

We need to strongly oppose the introduction of homophobic laws in countries like Russia, Nigeria and Uganda that on past experience are likely to drive those epidemics underground. And lastly, we need to urgently address the rising rates of infections in many key affected populations – men who have sex with men, people who inject drugs, sex workers and transgender women.

The AIDS 2014 Melbourne Declaration, launched on 17 May 2014, states that non-discrimination is fundamental to an evidence-based response to HIV and effective public health programs, and calls for immediate and unified opposition to these discriminatory and stigmatising practices. I call on each of you to sign the declaration.

Working together to end stigma and discrimination remains a fundamental part of our work to achieve what we continue to dream for – an end to HIV.

## References

- 1 Joint United Nations Programme on HIV/AIDS (UNAIDS). (2013). Global Report: UNAIDS report on the global AIDS epidemic 2013. UNAIDS, Geneva, 4.
- 2 *ibid.*, 47.



**Above:** 'A Cure for HIV: Dare to Dream?', Seminar with Professor Sharon Lewin, AIDS 2014 Local Co-Chair, at the India International Centre in New Delhi, India. ©IAS/Dhillon Photographics.

**Professor Sharon Lewin is Director of the Department of Infectious Diseases at The Alfred Hospital and Monash University; co-head of the Centre for Biomedical Research, Burnet Institute, Melbourne, Australia; and Director of the Peter**

**Doherty Institute for Infection and Immunity at the University of Melbourne. She is the local co-chair for the 20th International AIDS Conference (AIDS 2014), which will be held in Melbourne July 20–25, 2014.**

# Making history: the community heart of AIDS 2014

By **Brent Allan**

For those who have attended an international AIDS conference in the past, understand that this is a conference unlike many others. Sure, it is large and it is diverse, but what truly sets this conference apart is the role of community – both inside and outside the conference. From planning, through to the delivery and evaluation of the conference, the community is involved in all levels of decision-making, working alongside government and the scientific community as equal partners.

Included in our numbers are advocates, activists and agitators – both people living with and people affected by HIV. We are patients, clients, consumers, test subjects, service users and service providers.

For the first time in the conference's history, the vision for the Community Programme at AIDS 2014 explicitly endorses the greater and meaningful engagement of people living with HIV. We have also explicitly named those key populations disproportionately affected by HIV in the global response to this pandemic in our vision. Not only will we highlight examples of evidenced-based best practice in community responses to HIV, we will explore the innovation, creativity and entrepreneurial enterprise of promising practices.

In 1996, I stood outside a packed conference session room at the 11th International AIDS Conference in Vancouver where an impromptu television monitor had been set up to listen to David Ho present about something called 'combination therapy', using what was a new class of drugs called 'protease inhibitors'. I will never forget when a slide came up describing the results and the spontaneous cheers and applause that engulfed the conference centre.

These international gatherings provide a unique opportunity for the global

community of scientists, politicians, and people living with and affected by HIV to share their voices across a single conference program.

Although amazing achievements have been made during the last 30 years in the fight against HIV, now is the time to step up the pace. As part of the community response, we must build the skills we need to assess and develop the right 'combination prevention mix' for different populations. How do we match the social and epidemiological aspects of different infection patterns with the growing choices in biomedical, behavioural and structural interventions?

We need to turn our growing understanding of the science into policy, and in turn into highly efficacious community and clinical-based test and treat systems to ensure that people living with HIV are supported on long-term treatment success.

At the Barcelona conference in 2002 I was on a panel to hypothesise about the treatment and prevention nexus. The question, as it logically followed, was that if people with HIV were remaining undetectable then could there be a population benefit? The person sitting next to me was an amazing woman from Uganda who challenged my rather glib and elitist analysis. She spoke with passion about treatment access inequities in the developing world for people living with HIV, saying that its prevention effect was not hypothetical but a fantasy. We quickly became friends and she opened my eyes to issues in her country; we remain close friends today.

AIDS 2014 will provide an opportunity for people from key affected communities to network and consider how to take control of their localised epidemics – how to dismantle the barriers to putting in place what we

know to be effective prevention, testing and treatment programs.

This conference will call upon a global response to the human rights barriers, which are systemically disabling effective responses including legislative, regulatory and policy barriers as well as societal and cultural ideologies that often breed HIV stigma and discrimination.

We are at a tipping point in Australia and I believe we have the opportunity to achieve the 2011 United Nations Political Declaration targets. Achieving those targets would make the virtual eradication of new infections by 2020 a real possibility.

However I have no illusions.

We may not be able to radically transform societal mores but we can reform institutional barriers, we can work towards the goal of equal participation of people living with HIV in all aspects of civil society, and we can challenge ourselves and the roles we play as actors in research, government and civil society to ensure that our partnerships are healthy, robust and effective to enable a shared response which ensures that no one truly gets left behind.

At the last International AIDS Conference in Washington, I was convinced that we must do better to reduce HIV stigma and to develop resilience building programs for people living with HIV. I met two colleagues, one from Malaysia and another from Canada, and we hatched a plan in a hallway outside the session rooms to adapt a people living with HIV leadership development course for use in Australia. In two short years, this program had trained two dozen future leaders living with HIV across the country, all of whom are showing sustained resilience levels on standardised testing.



**Above:** Members of the AIDS 2014 Conference Coordinating Committee (CCC) during a planning meeting. The CCC makes top-line program decisions, including selection of plenary topics and speakers. Photos: © IAS.

I challenge you to take advantage of what AIDS 2014 offers, both in terms of content and connections. Currently there are over 150 events being planned within the Australian Cultural Program, ranging from public forums and events, to performances, photo exhibitions, and large public gatherings.

The aim of these activities is to ensure participants travelling to AIDS 2014 experience all that our city and country has to offer, in particular our vibrant arts, sports, music and cultural scene, our excellent public amenities and our educational and scientific facilities.

The Australian Cultural Program will be featured on the AIDS 2014 official

website – [www.aids2014.org](http://www.aids2014.org) – on a dedicated page entitled Welcome to Melbourne. Details will be accessed directly by delegates, sponsors, media and other interested parties as they start to build their conference schedule. Where appropriate, activity will also be listed on the City of Melbourne ‘What’s On’ website, [www.melbourne.vic.gov.au/whatson](http://www.melbourne.vic.gov.au/whatson).

I leave you with one final reflection about being a witness to history.

Within a week after the 1996 Vancouver conference, over 75,000 people living with HIV were moved from antibiotics and chemotherapy as treatment to an effective antiviral regimen, which

increased their immune system strength and spurred what is now referred to as the ‘Lazarus Effect’. This was when we first witnessed the truly transformative impact of antiretroviral medications on the lives of people with HIV.

**Brent Allan is Executive Officer at Living Positive Victoria and Local Co-Chair of the Community Programme Committee, International AIDS Society.**

# Our story, our time, our future: Indigenous culture, continuity and centrality to the global HIV response

By **James Ward**<sup>1,2</sup> and **Michael Costello-Czok**<sup>1,2,3</sup>

1 Baker IDI, Alice Springs; 2 Co-convenors of the Australian Aboriginal and Torres Strait Islander Organising Committee (AATSIOC) for the International Indigenous Pre Conference on HIV and AIDS – Sydney, Australia (July 17–19, 2014); 3 Anwernekenhe National HIV Alliance, Newtown, Australia

In 2014 the International AIDS Conference (AIDS 2014) will be held for the first time in Australia, in the city of Melbourne. As a prelude to AIDS 2014, Sydney will host the International Indigenous Pre-conference on HIV & AIDS, on the land and home of the Gadigal people of the Eora Nation.

The Pre-conference is being jointly convened by the International Indigenous Working Group on HIV & AIDS (IIWGHA) and an Australian Aboriginal and Torres Strait Islander Organising Committee (AATSIOC). International AIDS Conferences (IACs) have been held every two years since 2006, but this year is first time that the International Indigenous Pre-conference is an IAC independent affiliated event. This will significantly raise the profile of Indigenous people being part of not only the conferences, but of the global response to HIV.

The theme of this year's Pre-conference is 'Our Story, Our Time, Our Future', a name which reflects and promotes Indigenous peoples' culture, continuity and centrality in the global HIV response. The three-day event runs from July 17–19, and includes keynote speakers, plenary sessions, presentations and yarning circles discussing culture, HIV and health, prevention and education, policies, programs and leadership, plus research monitoring and evaluation.

There are two main satellite forums attached to the Pre-conference: a forum for people living with HIV, and a youth forum. There is also a luncheon for leaders from the Aboriginal health and HIV sectors, to bring together people who have an interest in what's happening with Indigenous communities and HIV,

but are not able to attend the whole conference.

Our international keynote speakers will speak to current and topical issues related to HIV care, prevention and treatment, bringing with them experiences from Canada, the USA and New Zealand.

Over 250 delegates have registered to attend, from locations including Mexico, Guatemala, Chile, New Zealand, Canada, the Pacific, USA – as well, of course, from Australia. We are pleased to announce that we will be hosting First Peoples Elders from communities around Australia to be part of our conference, whose responsibility it will be to influence and spread the word among Elders groups nationally about HIV.

## Why the need for an Indigenous conference?

A conference focusing specifically on Indigenous issues is important for a number of reasons.

### 1. Maintaining identity

Indigenous peoples' identities are contested globally, both from within communities and, externally, from international bodies, through questions such as 'who is Indigenous and who is not?'

In many countries Indigenous populations have endured multiple colonisation periods in history, and people's rights to be recognised as Indigenous are far from achieving resolution. This contestability lies at the heart of our conference, which provides an opportunity for all self-identifying Indigenous peoples (irrespective of their

nation state's stance) to come together to discuss strategies for moving forward as Indigenous peoples in the context of a world with HIV.

Quite often under a United Nations (UN) definition, Indigenous peoples' identity gets lost in other population groups and they're not identified as Indigenous – they're identified under other sub-groups. So when the International AIDS Conference is held in a country like Australia or Canada, where there's a resourced Indigenous population that is participating in the HIV response in many different ways, this presents an important opportunity for greater focus on Indigenous issues and Indigenous Identity.

For Indigenous people, a conference like this is not only about stepping up the pace in the HIV response, it's also about acknowledging who we are as people in that response: what we've done in the past, and where we need to go in the future. We wanted to make the Indigenous Pre-conference theme inclusive, and ensure that Indigenous people's culture is a part of the conference. Recognising the centrality of maintaining identity is bound to enable Indigenous people to participate more effectively in the larger context of the conference.

### 2. Achieving recognition

A key aim of the conference is to raise the profile of the issues affecting Indigenous people globally. Very few high level documents relating to HIV, especially those produced by UNAIDS or the World Health Organization, mention Indigenous people as a key or recognised population at risk of HIV.



## OUR STORY, OUR TIME, OUR FUTURE

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Of course, being Indigenous doesn't place someone at special risk of HIV per se. It is the inequalities in health and the social determinants of health that profoundly affect Indigenous people, placing Indigenous people in special and urgent need of being recognised as a key population in international agency documents. If Indigenous people don't recognise ourselves in these documents then we don't see HIV.

There are a range of different issues around HIV that affect Indigenous communities differently. One country's success may be another country's barrier. A key topic for discussion at this year's Pre-conference is the impact of treatment as prevention (TasP) on Indigenous people. Different countries are at different stages in their understanding of TasP, and coming to grips with just how it's going to be implemented.

Specific issues relating to Indigenous people living with HIV, and how people are dealing with those issues nationally and internationally, are always at the forefront of every Indigenous Pre-conference. The idea is that raising the profile of Indigenous people living with HIV internationally will build a stronger network, which can be utilised to assist some of the other developing Indigenous communities that participate in these conferences.

### 3. Securing our future

It is essential that we look to the future. While in Australia we have been successful in our approach so far, with HIV rates of diagnosis similar to non-Indigenous people, the fact that our communities remain vulnerable to HIV lays somewhat dormant, and innovation is missing in current HIV prevention responses. We know what these vulnerabilities are. We know what we

need to do, such as tackle persistently high rates of other sexually transmitted infections (STIs) – particularly in remote communities. We know the other factors that make people sick in our communities – dispossession, poor access to health care, racism, stigma, discrimination; and we are familiar with the many social determinants of health affecting our communities: overcrowded housing, poor education and lower incomes. Our Sydney conference is an important opportunity to discuss these issues in depth.

A major focus area for AIDS 2014 will be national commitment and responses to the targets of the 2011 United Nations Political Declaration on HIV/AIDS. As global Indigenous communities galvanise towards these targets, the varying research, monitoring, prevention and treatment initiatives of countries will impact successes and barriers.

At our Sydney conference we will launch the Eora Action Plan, a charter for us to commit to into the future. The Eora Action Plan (so named because we are meeting in the Eora nation, home of the Gadigal peoples of the Sydney basin) sets out clear goals:

1. Reduce the number of newly diagnosed HIV cases among Aboriginal and Torres Strait Island peoples by 50%
2. Eliminate all mother-to-child transmission of HIV among Aboriginal and Torres Strait Islander peoples
3. Ensure antiretroviral treatments are available and accessible and correctly utilised by 80% of Aboriginal and Torres Strait Islander people living with HIV
4. Move toward reducing rates of other STIs in Aboriginal and Torres Strait Island communities by 50%

5. Reduce rates of sharing injecting equipment by 50% among Aboriginal and Torres Strait Islander people who inject drugs.

In Sydney, we will also launch the first national Aboriginal and Torres Strait Islander youth committee, whose job it will be to mobilise young people in the areas of healthy messaging around sexual health and HIV, STIs and reproductive health rights using social media as a main platform. The committee, called ANTHYM (Aboriginal Nations Torres Strait Islands Youth HIV Mob), is an exciting initiative of both AIDS 2014 and the International Indigenous Pre-conference, and will serve us well into the future by ensuring that young people's voices and perspectives are heard in future planning.<sup>1</sup>

### AIDS 2014

After Sydney, many of our conference delegates will head on down to Melbourne to participate in AIDS 2014. The AIDS 2014 main conference program includes a number of Indigenous-led sessions, including on leadership, and James Ward will be the first Indigenous person to present on Indigenous peoples issues in a main plenary session at an International AIDS Conference, on Wednesday 23 July.

A major focus of Indigenous activities at AIDS 2014 is *Djamabanna Ngargee Birrarung Marr*, the Indigenous Peoples Networking Zone at the Global Village. The zone, which runs for the whole week of the conference, includes a program of activities ranging from cultural performances to informal discussions and interviews with people from the International Indigenous Working Group on HIV & AIDS

(IIWGHA), the local Australian Aboriginal and Torres Strait Islander Organising Committee (AATSIOC), and relevant people associated with the International AIDS Conference.

A range of cultural activities has been organised around Melbourne to raise awareness about the conference and its objectives and outcomes. There'll be community forums, social events, and gatherings. The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) has taken a leading role in organising and working with IIGWHA to plan and develop the Indigenous Peoples Networking Zone and local events.

On Monday 21 July the First Peoples Welcome event for conference delegates will be held at Bunjilaka, Victoria's award winning Aboriginal Cultural Centre at Melbourne Museum – featuring guests from VACCHO and its members, Aboriginal and Torres Strait Islander delegates from across Australia and First Peoples' representatives from around the world. This event is of significant cultural importance to Indigenous people. Welcome to country is about Aboriginal people being welcomed onto the land before business takes place, and it is also hugely important for our international guests.

We invite you to come and join Aboriginal and Torres Strait Islander peoples along with international First Peoples from Canada, North America, Chile, Guatemala, Fiji, Aotearoa and many other Indigenous Nations to meet, discuss, learn and share information about HIV, sexual health, sexuality and harm reduction in our communities.

### After the conference

We have planned a legacy strategy to build on the tremendous opportunities that hosting an international conference can bring. After the Pre-conference and AIDS 2014 have finished we will announce an initiative that aims to bring about improved understanding and awareness of HIV in the broader Aboriginal and Torres Strait Islander community



through an annual Aboriginal and Torres Strait Islander HIV Awareness Week. Each year for the next four years, beginning in December 2014 and coinciding with World AIDS Day, we will run a week of activities in communities across Australia.

For Sydney and Melbourne we have commissioned nine pieces of art of special significance to HIV from renowned Aboriginal and Torres Strait Islander artists. These artworks will be displayed during both the Sydney conference and at the Indigenous Peoples Networking Zone in the Global Village at AIDS 2014 and will continue to be showcased at future HIV Awareness Weeks.

AIDS 2014 has provided a massive opportunity to reinvigorate our responses regarding HIV within our communities as well as an opportunity to motivate the big agencies involved in HIV to include Indigenous peoples as a key population in future developments. It raises the opportunity for us to be central to our HIV responses and for us to celebrate our successes.

Drop by at *Djamabanna Ngargee Birrarung Marr* to have a chat or participate in many of the activities planned for AIDS 2014.

### Acknowledgements

The Sydney International Indigenous Pre-conference is funded by the NSW Ministry of Health – HIV, STI and Viral Hepatitis Harm Reduction and Viral Hepatitis Branch, Centre

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The AATSIOC members include: James Ward, Baker IDI Heart & Diabetes Institute (Baker IDI); Michael Costello-Czok, Anwernekenhe National HIV Alliance (ANA); Mark Saunders, National Aboriginal Community Controlled Health Organisations (NACCHO); Michelle Tobin, Positive Aboriginal & Torres Strait Islander Network (PATSIN); Sallie Cairnduff and Darren Braun, Aboriginal Health & Medical Research Council of NSW (AH&MRC); Peter Waples-Crowe, Kat Byron and Andrew Bamblett, Victorian Aboriginal Community Controlled Health Organisation (VACCHO), Trevor Stratton, International Indigenous Working Group on HIV/AIDS (IIWGHA) Jessica Danforth and Krysta Williams Native Youth Sexual Health Network, James Saunders Mopoke Media and ANTHYM coordinator, Victor Tawil and Meggan Grose, NSW Ministry of Health.

### Endnote

- 1 Further information regarding ANTHYM is available at [www.anthym.org](http://www.anthym.org) or on Twitter @ANTHYMAUS

Further information about the 2014 International Indigenous Pre-conference on HIV & AIDS is available at [www.indigenoushivids2014.com](http://www.indigenoushivids2014.com)

## Creating an enabling environment: regional networks and community organisations are leading the way

Community organisations and networks are essential to achieving effective HIV responses, and a diverse, strong and active civil society is leading the way in Asia and the Pacific.

The Australian Federation of AIDS Organisations (AFAO) operates an International Program based in Bangkok, which implements advocacy, capacity building and community mobilisation projects in collaboration with key regional networks and organisations throughout the Asia and Pacific regions. Below, some of AFAO's key community partners working across Asia and the Pacific have submitted brief statements to welcome delegates attending AIDS 2014 to our region.

### Asia Pacific Council of AIDS Service Organizations (APCASO)



By **Moi Lee Liow**,  
Executive Director,  
APCASO

In recent years, there have been many success stories in response to HIV and AIDS across Asia and the Pacific. There is progress in areas such as reducing new infections, expanding antiretroviral (ART) coverage, increasing domestic financing, and attempts by governments to address stigma and discrimination. In this region, civil society and community leadership – among the most dynamic, prevalent and organised in the world – is credited with contributing to this success. APCASO is confident that we have made some valuable contributions to this enviable situation, working to strengthen community capacity to engage in national processes and advocate at the national and regional level.

APCASO's partnership with AFAO is an example of a productive and

synergistic North-South collaboration. AFAO has also provided APCASO with valuable technical support that has enabled us to do our work better, with improved linkages to global policy and technical knowledge.

From the initial APCOM and AFAO partnership on the AusAID HIV/AIDS Partnership Initiative (AHAPI) program in 2006 to the current Community Advocacy Initiative (CAI) program, dozens of community-based organisations in Cambodia, China, India, Indonesia, Laos and Vietnam have gone through a dedicated capacity-development process of coaching, mentoring and training that has progressed and increased advocacy and effective engagement in strategic areas such as domestic HIV financing and investments, human rights of key populations, and employment discrimination affecting people living with HIV. Some of these issues will be discussed at sessions in Melbourne.

In spite of many success stories, Asia and the Pacific still has many pockets of resistance affecting key populations, in particular men who have sex with men (MSM), people who use drugs, sex workers and transgender communities. Recognising this, the CAI program has adopted an inclusive approach to ensure these communities take centre stage in CAI program activities.

At the 2014 International AIDS Conference in Melbourne this July, 25 community advocates and activists from APCASO partner organisations will participate in the Australia Awards Fellowships (AAF) program. The AAF will strengthen participants as

effective leaders in their work towards equal community partnerships in their country's HIV response. The results of investments in an enabling environment are informed, empowered and committed community leaders.

**To learn more about Australia Awards Fellowships programs, see the articles on pages 56 and 58. Moi Lee Liow discusses the Global Fund's new funding model in *HIV Australia* online, available at: [www.afao.org.au](http://www.afao.org.au)**

### Asia Pacific Coalition on Male Sexual Health (APCOM)



By **Midnight Poonkasetwattana**,  
Executive Director,  
APCOM

Welcome to the Asia-Pacific region! It's been ten years ago since the International AIDS Conference was held in our region, in Bangkok in 2004. At the time the response to HIV among men who have sex with men was in its infancy – indeed it was not until 2007 that APCOM (Asia Pacific Coalition on Male Sexual Health) was formed to highlight the need to address rising HIV transmission rates among men who have sex with men.

As a coalition, APCOM recognises the need to work in collaboration across different sectors and organisations to effectively address HIV issues; this includes working together with civil society, development agencies, government, United Nations system and technical experts. In order to truly address the challenge of HIV, we need to work together towards creating an 'enabling environment' to confront stigma, discrimination, violence and social exclusion of men who have sex with men and transgender people. The promotion and protection of rights to

life-saving health services is crucial, as is investment in the response – especially the resourcing of community organisations. Of key and fundamental importance is the involvement of men who have sex with men and transgender people in framing and implementing responses to prevent and treat HIV, improve sexual health, and reduce stigma and discrimination.

We hope you have an opportunity to get to know our work in the region through our booth in the AIDS 2014 Global Village, or by attending our sessions at the conference.

**Asia Pacific Transgender Network (APTN) – Making Trans people count in the HIV/AIDS Response**



By **Joe Wong**,  
**Project Manager,**  
**APTN**

Social researchers estimate that the number of transgender people living in Asia and the Pacific is approximately 9–9.5 million; however, the actual population size remains undetermined.

Transgender people are an integral part of the traditional culture of several countries in Asia and the Pacific and in some settings *hijra*, *waria*, *kathoey* and *fa'afafine* have been accepted into traditional daily life. Discrimination remains entrenched, however, with transmen and transwomen encountering a wide range of challenges in accessing equitable healthcare – including to general and transitional mental health care and sexual health care. The challenges facing transmen are not generally acknowledged and are under-researched.

Discrimination and the lack of societal acceptance, understanding and support of gender identification and varied sexual orientation remain persistent barriers for transgender people exercising the right to access health, education, employment and social services.

Transgender people, in particular transgender women, face higher risk of HIV infection – 49 times higher than that of the general adult population<sup>1</sup>, with many engaging in sex work or transactional sex because of employment discrimination and lack of economic opportunities. Data from countries in the region, for example, Thailand, shows that transgender women have high rates of substance use. The Asia-Pacific Transgender Network (APTN) and United Nations Development Programme (UNDP) 2012 report, *Lost in Transition – Transgender People, Rights and HIV Vulnerability in the Asia-Pacific Region*, suggests that HIV prevalence rates are as high as 68% among transgender communities.<sup>2</sup> Information from one South East Asian city indicated that between 2003 and 2007 HIV prevalence among transgender people rose from 25% to 34%.<sup>3</sup> Little is known about incidence and prevalence among transgender men in the region.

Transgender people are rarely included as a separate key population in national HIV biological and behavioural surveillance or population size estimation exercises, limiting opportunities to respond effectively. Improved evidence and data are crucial to inform effective programming that meets the real needs of transgender communities in Asia and the Pacific.

The mission of APTN is to enable transgender women and men in Asia and the Pacific to organise and advocate for improvements to health, protection of legal, social and human rights, and enhancement of social wellbeing and quality of life.

In February 2014, APTN organised its second major regional consultation, designed to review the situation of transgender people and identify areas for accelerated action. The following priorities were identified by community leaders:

- increase healthcare provision and access
- reduce stigma and discrimination in healthcare provision

- expand quality training for health and other key service providers working with transgender people
- produce and disseminate content appropriate and specific information to health and other service providers on transgender issues.

Transgender health needs (mental, transition, sexual and general healthcare) must be addressed holistically and comprehensively and linked to the broader context of economic empowerment through providing meaningful employment opportunities and access to education, as well as access to and enjoyment of social protection benefits.

APTN continues to work for the rights and recognition of transgender people through rights based advocacy, policy influencing, and engagement with community organisations at the regional and country level, ensuring that stakeholders and partners have the evidence, understanding and alliances necessary to enable transgender communities across Asia and the Pacific to design and lead an effective response to HIV.

**Youth Voices Count (YVC)**



By **Lieu Anh Vu** (top),  
**Interim Network Officer,**  
**YVC and Phillip Salvador,**  
**Interim Project Officer, YVC**

As data in Asia and the Pacific continues to indicate that young men who have sex with men and transgender people are at high risk of HIV infection, it is imperative that attitudes, policies, and practices continue to stimulate and support effective and efficient functioning of organisations and individuals working on issues surrounding HIV and other health services.

In urban meccas such as Bangkok, Thailand, Ho Chi Minh City, Vietnam, and Chongqing, China, young men who have sex with men have high HIV prevalence rates, with the primary mode of transmission being unprotected sex. Young people face additional barriers to accessing services due to criminalisation of male-to-male sex in 19 out of 38 countries in the Asia-Pacific region<sup>4</sup>, the non-recognition of gender identity of transgender people, and intense stigma and discrimination in their environments<sup>5</sup>. HIV prevalence has been increasing among young transgender people over the past several years<sup>6</sup>, indicating that young transgender people remain an invisible population whose needs are not being addressed.

Laws that require parental consent to obtain HIV testing and counselling for young people under 18 in some countries in the region continue to

create widespread challenges for young people attempting to access health services. In addition, men who have sex with men and transgender people aged 18–29<sup>7</sup> report facing unique self-issues and intense self-stigma, which further increase their HIV vulnerabilities.

When we talk about stepping up the pace in reversing the HIV epidemic, we must also guarantee that platforms for young key populations exist and are working. Youth Voices Count, a youth initiative led by young men who have sex with men and transgender people, has been at the forefront of giving a loud voice and a proud face to the issues that directly affect young men who have sex with men and transgender people by way of advocating, mainstreaming, and providing a regional platform for the network's strong membership in 19 countries around Asia and the Pacific. These efforts will not be fully realised unless we ensure a working enabling environment is created and sustained.

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Sex workers from Asia and the Pacific calling for decriminalisation of sex work at ICAAP11, Bangkok 2013. Photo: Janelle Fawkes. See the article on page 75, where Maria McMahon, Scarlet Alliance's International Program Manager, discusses sex worker organisations' partnerships and collaborations for capacity development.

# What AIDS 2014 can learn from Melbourne and what Melbourne can learn from the world

By **Michael Bartos**

Nineteen eighty-four was a pivotal year for Melbourne's AIDS response. From 1981 to 1983 there was a kind of 'phoney war' about AIDS in Australia. People kept up with the latest news from the US, but while some key gay community journalists and public health bureaucrats were preparing the way, for most Australians – including those among the gay community – AIDS still felt far away.

The first harbinger of a shift to a more urgent response came in mid-1983 with the formation of the AIDS action groups prompted by the Red Cross Blood Bank's proposal to ban gay donors. But it was not until November 1984, when the ultra-conservative Queensland government decided to make political capital out of the HIV infection of four infants through blood from a gay donor, that the AIDS response really took hold. Within a month, a full-scale emergency response was underway with many of the characteristics that continued to propel its success into the subsequent decade.

Thirty years on, many of the things we take for granted in today's HIV response have become so commonplace it is hard to recall that they were the sites of struggle and heroic invention in the period of the mid-80s: safe sex for example, and even community involvement in a 'medical' issue.

The key question that was defined in that period in Melbourne, and Australia more widely, was one of power – who was to control the AIDS response: paternalistic public health doctors or mobilised, affected communities? In resolving this question largely in favour of communities, the practice of public health and health promotion was fundamentally changed, for the better.

Community had on its side fundamental political skills of organising – disciplined, sophisticated use of the media and

viable, nuanced positions which were saleable to elected politicians. Underlying these tactical strengths was a more basic shift in the balance of power through the ability of the community sector to reshape the notion of expertise. This entailed a mastery of the traditional sources of expertise: gay community journalists became the most well-read HIV medical experts in the country, able to engage more traditionally medically-qualified experts on their own terms and often trumping them with more up-to-date information obtained through international community networks.<sup>1</sup> In addition to a strictly medical expertise, the capacity to speak for and be embedded in the communities most affected became recognised as a crucial aspect of the expertise necessary to the AIDS response.

The struggle over control coalesced around two major elements: HIV testing, and the development of health promotion using culturally appropriate risk-reducing approaches.

Today, the mantra that HIV testing is the gateway to HIV prevention and care is so often heard that it is hard to even imagine that one of the most successful responses to HIV/AIDS in the epidemic's history gained its initial power and leverage precisely through resisting testing.

One of the reasons the initial emergence of AIDS among gay men caused such moral and political panic was that gay men were not a readily identifiable group. The classic public health tools in response to an emerging communicable disease are screening and quarantine. AIDS was identified as a singular disease rather than just random mortality because by the late 1970s communities of self-identifying gay men had emerged in Los Angeles,

New York, and San Francisco (among other places) and doctors serving these gay men – many themselves gay – noticed unusual patterns of disease and death. It required self-identification because gay men's risk was constituted by private sexual practice, not easily identified markers like race or specified geographic location.

No test for gayness existed, but soon a test for HIV was developed and came into use in 1985 and Australia was one of the early adopters, at least for blood screening. Once an HIV test became available, the issue was whether the population of gay men could be 'flushed out' by requiring them to test. Policies around antibody testing rapidly polarised, including within community organisations. The AIDS Council of New South Wales was inclined to advocate in favour of testing, while the policy stance of the Victorian AIDS Council was that while individuals should be able to choose to test if they wished, there was no compelling reason in favour of testing – a position it maintained until around 1988 when clinical evidence and early results from the use of AZT suggested there were health benefits for those testing positive.<sup>2</sup>

The power over testing became a key point of leverage in getting community a seat at the public health table. Initially, the national and state bodies charged with responding to AIDS refused petitions for community representation. In 1983 the National Health and Medical Research Council's AIDS Task Force advised the Health Minister that 'there was no place for representation of individuals who do not have the scientific understanding or discipline to contribute to the consideration of the issues on hand'.<sup>3</sup>

The introduction of compulsory notification of HIV infection in New

South Wales and Queensland in 1985 ignited testing controversies, and the inclusion of mandatory testing in Victoria's 1987 HIV legislation was only defeated after a concerted lobbying effort. On one side, traditional public health authorities took testing as an article of faith. For them, surveillance was a necessary starting point for any response. Gay community saw the issue differently: what was the use of testing if there was no effective treatment, if it exposed people to discrimination, and especially if testing undermined the solidarity between those infected and uninfected at a time when the community was inventing safe sex as a mass response.

The invention of safe sex was the second significant realm of political struggle over AIDS in the mid-1980s. The invention of safe sex has been widely canvassed, but it is worth recalling the salient features of Melbourne's version. In common with most, it was sex-positive, taking as a given that gay men should be supported to continue to enjoy sex. Exhortation to abstinence was considered unrealistic. In that sense, it was from the outset a risk-reduction rather than a risk-elimination strategy. Once the debate over a single viral cause or multiple germ and lifestyle factors was settled with the discovery of HIV in mid-1984, consensus rapidly developed that the most important priority was to get gay men to use condoms for anal sex, regardless of HIV status. Strategies such as reducing the number of partners, increasing the lighting in gay saunas (as proposed in San Francisco) or closing them altogether (New York), or opposing drug and alcohol use were dismissed as moralistic and hygienicist.

A series of innovative HIV education efforts were put into effect by the

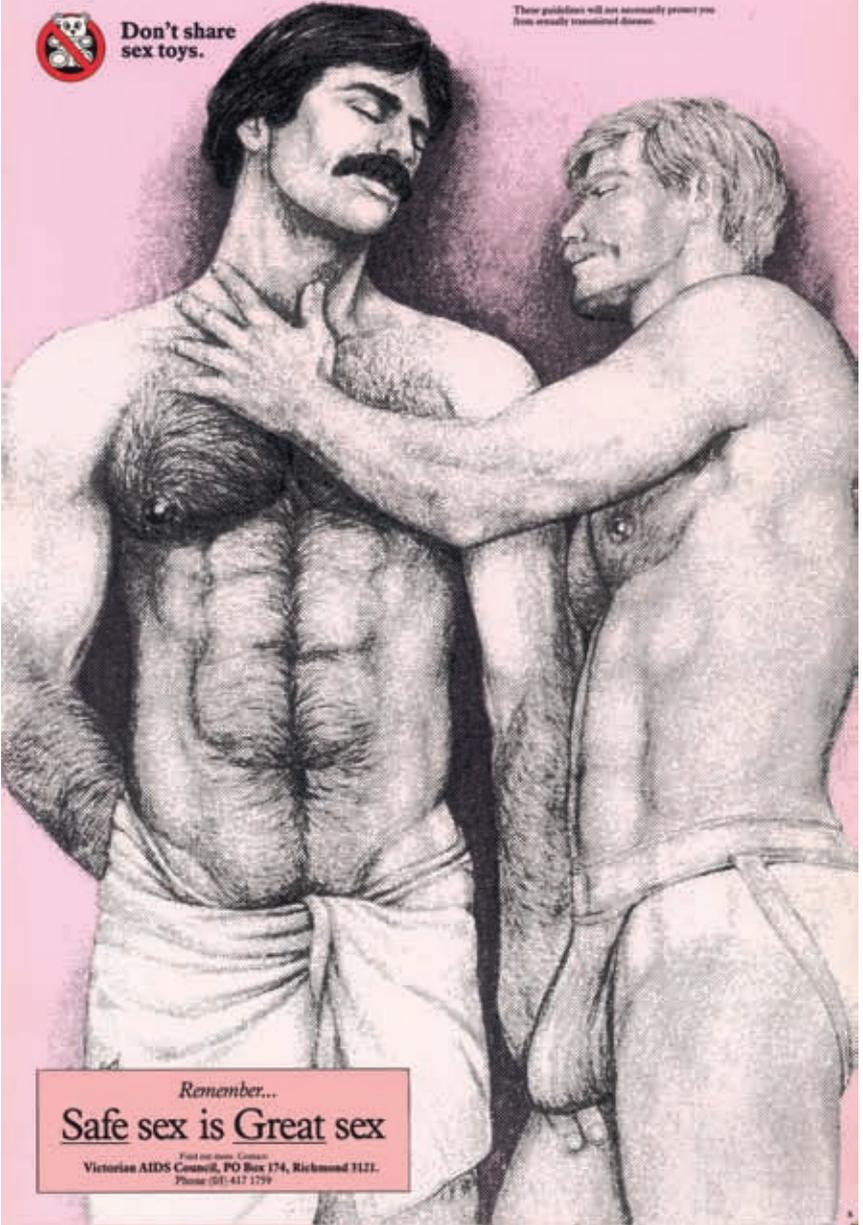
**Pictured right:** Displayed in gay clubs and saunas, this poster was part of the Victorian AIDS Council's first education campaign, and one of the first safe sex posters devised by a non-government organisation in Australia. Image: Australian Lesbian and Gay Archives.

# Great Sex!

## Don't let AIDS stop it

-  **Don't come inside his arse.**  
Avoid the exchange of semen.  
Use a condom when fucking.  
Insist your partner does the same.
-  **Don't come in his mouth.**
-  **Don't rim.**
-  **Don't fist, if you intend to fuck afterwards.**
-  **Don't share sex toys.**
-  **Masturbation is hot and safe.**
-  **Staying healthy is important.**  
Learn about nutrition, proper sleep, how to handle stress, get plenty of exercise, avoid drugs, cut down alcohol consumption, and get regular check-ups.
-  **Affection is our best protection.**
-  **Don't donate blood.**

These guidelines will not accurately protect you from sexually transmitted diseases.



Remember...

### Safe sex is Great sex

First safe sex poster  
Victorian AIDS Council, PO Box 174, Richmond 3121.  
Phone (01) 417 1279

Victorian AIDS Council in its first years (it was launched in December 1984). The Council's first education campaign included a poster which read, "Great Sex! Don't let AIDS stop it" and a pamphlet titled *AIDS: Trying to Reduce the Risk*. Outreach activities were conducted in public places used for sex. A genre of sexually explicit 'pornucation' was created.<sup>4</sup> Alcohol and drug use was addressed but not discouraged: instead, based on research that showed alcohol and drug use were part of intentional strategies to give internal 'permission' for unsafe sex, gay men were advised 'alcohol and drugs: no excuse'. Youth campaigns carefully courted controversy with a 'two boys kissing' poster driving recruitment into youth peer education groups. And by the end of the 1980s, HIV status was explicitly incorporated into HIV prevention programming with the appointment of an HIV-positive prevention officer and a 1992 campaign under the slogan 'one of us has HIV, two of us have safe sex'.<sup>5</sup>

New HIV infections in Melbourne peaked in around 1985. They were largely among gay men. No doubt the simple fact of news about the presence of HIV accounted for some of the change in sexual practice that reduced transmission. But at the same time, an active, politically engaged mass response supported through community organising and in tune with changing norms must have made a major contribution.

2014 is not 1984. Political organising has taken a backseat to the business of AIDS, with the latter driven largely by increasing access to antiretroviral therapy (ART) across the world. In 2012 total international and domestic AIDS spending in all low and middle-income countries was around \$19 billion, 53% of which came from domestic sources – the main source of recent spending growth since international aid increases stalled from 2009.<sup>6</sup> In comparison, in 2012 the US alone spent \$21.3 billion on its domestic HIV epidemic.<sup>7</sup> The share of AIDS resources going to treatment has been steadily increasing, and that share will continue to increase through the

inevitable logic of the cumulative cost of life-long therapy, especially as consensus suggests first-line ART costs have pretty much bottomed out.

HIV prevention is not the same in the era of mass treatment access as it was before. But as Kippax and Race presciently argued a decade ago, the increasing place of medical technologies, whether testing or ART, do not supplant the social, they just change the ground over which social and sexual practice is negotiated.<sup>8</sup>

For much of the globe, community attempts to seize power over the AIDS response have been an uphill struggle. Development assistance has been a double-edged sword. It has brought with it much needed resource assistance which has enabled millions of HIV infections to be averted and millions of lives to be prolonged through ART access (after the international aid community deemed in the early 2000s that it was prepared to fund treatment). But with the resources has come the dreaded development expert, inserting another layer of power getting in the way of local solutions to collective action problems.<sup>9</sup>

For many in the AIDS world, the turn to treatment has been embraced with a sense of relief that medical technologies can leave the messy business of politics behind. But this just blinkers out the real negotiations of power that happen on a macro scale when, for example, procurement contracts worth billions are negotiated out of sight, or on a micro scale as people negotiate the minefields of doctors' instructions, neighbours' contempt (or support) and the prospect of asking their new sexual partner to test him/herself for HIV.

The epidemic's first decade was characterised by medicine's impotence in the face of HIV and a humility that came with it. The third decade has been the opposite. Despite the measured restraint of the respective lead researchers, the last two International AIDS Conferences succumbed to an overblown medical triumphalism – in Vienna with the CAPRISA microbicide trial results, and in Washington with the

continued over-selling of HPTN-052<sup>10</sup> and treatment as prevention.

In Melbourne, perhaps the weight of history will be able to exercise some counter-balance.

**Michael Bartos was President of the Victorian AIDS Council from 1993–1994. He is currently UNAIDS Country Director in Zimbabwe.**

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# A time to be loud and furious: AIDS activism in Australia

By **Dr Abigail Groves**

Films like *Dallas Buyers Club*, which won Matthew McConaughey an Oscar®, and *United in Anger*, a history of ACT UP, have turned HIV activists into heroes. But what is striking about these movies is that the events they depict are placed firmly in an historical context. This is a time that has passed. The urgency of the AIDS crisis has largely, and thankfully, disappeared – at least in the developed west. Yet there is a certain nostalgia for the innovation and excitement that AIDS activism generated.

‘People are suddenly interested in talking to me,’ says Lloyd Grosse, Sydney DJ and former HIV activist. ‘It’s like we are the heroes of the AIDS movement’. Grosse lays claim to being the first Australian to come out publicly as HIV-positive and an old, yellowed copy of the *Sydney Star Observer* suggests he may be right. It carries a picture of Grosse in an ad encouraging gay men to ‘take control’ and get tested for HIV. The piece now seems innocuous – another ad for HIV services, of the kind familiar to any reader of the gay press. More striking to me are the bouffant hairstyles and high-waisted pants of the early ‘90s. But there is something from the *Sydney Star Observer* of twenty years ago that I had forgotten: the awful, gut-wrenching death notices. ‘There was one period,’ Lloyd says, ‘when the Bobby Goldsmith Foundation had five clients and seven friends die in one week. One week.’ Events like these put Lloyd Grosse’s decision to come out in perspective.

‘An activist,’ writes Eve Ensler, author of *The Vagina Monologues*, ‘is someone who cannot help but fight for something. That person is not usually motivated by a need for power, or money, or fame,

but in fact driven slightly mad by some injustice, some cruelty, some unfairness. So much so that he or she is driven by some internal moral engine to act to make it better.’

Anger and a sense of injustice are recurring themes in the accounts of AIDS activists. The spectre of death and dying added urgency. ‘They were terrible times, just terrible. I was angry,’ says Paul Kidd, a former President of Living positive Victoria and self-identified “stirrer”. Anger, Paul feels, was an appropriate response. ‘Anger is what gets people off their arses in the first place, so it has a motivating role. Second, the expression of anger is an important part of activism. There’s a time to be respectful and polite, and there’s a time to be loud and furious.’ Being a gay man in the 1980s and early 90s was one such time.

‘At one stage,’ Lloyd Grosse recalls, ‘ACON was telling people not to get tested, because there was nothing that they could do to help us. And there was a real fear, at that time, that the government would put us in quarantine or something like that.’ Grosse later did get tested and, despite assurances that he was not high risk, tested positive. With a background in the union movement, activism came naturally to him. Already a volunteer at AIDS organisations in Sydney, he became involved with PLWHA (NSW) (today known as Positive Life NSW) and then ACT UP. Similarly Paul Kidd, who was diagnosed in the early 1990s, says that, ‘I’ve always been a politically aware/outspoken person and AIDS was the issue du jour in the gay community. I thought I was going to die and I wanted to make some noise before I did’.

Not everyone had such a background, though. Lyle Chan is a classical composer who found himself in the middle of an emergency. ‘I couldn’t stand by,’ says Chan. ‘My friends were dying. I saw ordinary people turn themselves into activists, so I did the same. The prevailing atmosphere was, “we will do whatever it takes”. I was a musician, but I also had a background in molecular biology – though no one was an expert in AIDS back then,’ he adds. ‘The doctors and researchers had an advantage because of their medical training but still, they knew no more about AIDS than the activists did, because we made a point of being well-informed.’ After coming to Australia from America, he joined ACT UP and also ran a ‘buyers’ club’ at ACON, importing drugs from the US unavailable in Australia.

Chan had over 400 clients. ‘The AIDS Council gave it a euphemistic name: the Treatments Access Scheme. The buyers club operated under cover of a provision in federal law that allowed people to import certain medical drugs under certain conditions. The law was designed for drugs manufactured by legitimate drug companies – but I was importing ddC [dideoxycytidine – an early antiretroviral medication] made in underground laboratories in violation of multiple drug patents, while the official drug company and the Australian government took their time working out how to supply it’.

Access to treatments was the big issue for people with HIV in Australia, as it was elsewhere. Access to treatments gave ACT UP its moment in Australia. In Australia, the early trials of AZT – the first antiretroviral drug approved for use by the US Food and Drug

Association – were run on a quota system. This meant that those who were unable to access the trial were left with nothing, which incensed activists. ‘The process for approving new drugs was very bureaucratic and took no account of the nature of the illness. You could have a drug for dandruff and a drug for cancer and they were both treated in exactly the same way,’ explains Lyle.

Treatment issues also gave the impetus to ACT UP, the direct action group which had proved effective in the US. However, ACT UP was never as popular or widespread in Australia as it was in the US. This may have been due to the effectiveness of the Australian government’s response to HIV. With a Labor government in power during the 1980s, Australia benefitted from progressive leadership on HIV issues. ‘It was really down to three people,’ says Lloyd Grosse. ‘Neal Blewett was the Health Minister. Bill Whittaker was a great advocate. And Bill Bowtell who was Blewett’s advisor – he was in the right place at the right time.’ It was through their leadership that Australia adopted harm minimisation policies such as needle exchanges, and funded organisations like the AIDS Councils to provide community-based education and services.

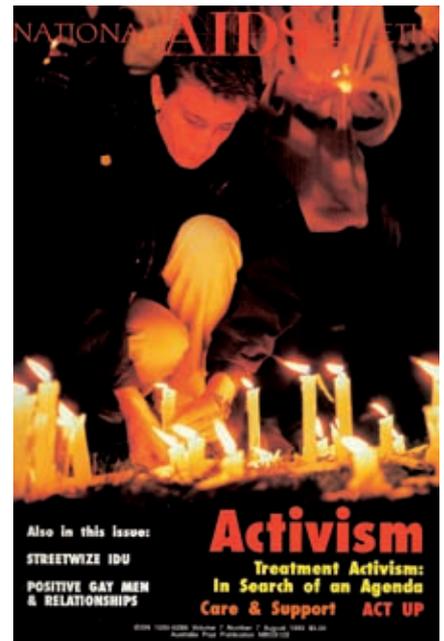
But these community-based services could themselves become targets of attack from activists. ‘A lot of my anger was directed at the AIDS movement,’ says Lloyd Grosse. ‘They were too caught up with their careers – they would never stick their necks out.’ Lyle Chan says ACT UP deliberately cultivated its image as the ‘lunatic fringe’ of the HIV movement. ‘ACT UP had a love-hate relationship with organisations like ACON,’ he recalls. ‘ACT UP criticised the HIV organisations and could also say and do things that other groups couldn’t. But we also knew that our extreme protests against government officials and drug companies would send them straight into negotiations with ACON (the AIDS Council of NSW) and AFAO

(the Australian Federation of AIDS Organisations) to get relief. These organisations had the same goals as ACT UP but were less antagonistic. ‘The range of players – government, medical professionals, drug companies, NGOs and activist groups – made for a volatile environment, especially when sex and personal relationships were added into the mix.

Where has it gone, this anger? Lyle Chan says he made a conscious decision to leave activism behind, once it became clear that the protease inhibitors, the new generation of antiretroviral drugs, would ‘rescue people from the toilet’. ‘Activism is an attempt to reach some kind of normality,’ he reflects, ‘that you feel is being denied for some reason. Once it became clear, between 1994 and 1996, that we were no longer fighting against a constant backdrop of death, it became possible to imagine a future where every day was not a state of emergency. Some activists continued, working in Asia for instance, where the crisis continued for different social reasons. But I felt my work as an activist was done, and with normality came the responsibility of returning to my true purpose, which was to write music.’ Chan has since written an acclaimed string quartet memoir of his years as an AIDS activist.

Lloyd Grosse is no longer involved in HIV issues, either, though he says he took longer to move on. ‘The war ended,’ he says. ‘People are no longer dying, so in a sense we won. I have returned to my core, which is social justice issues.’

Paul Kidd, who became involved in AIDS activism a little later than the others, says he is no longer angry – at least, not about HIV issues. ‘Anger doesn’t seem right in the current context because the stakes just aren’t as high as they once were: people are not dying.’ Kidd, however, still writes about HIV issues. ‘I think our AIDS organisations have become dreadfully risk-averse,’ he says. ‘Too many of them are more concerned about upsetting



**Above:** The AIDS candlelight vigil in Sydney, as depicted on the cover of the *National AIDS Bulletin*, November 1993. The NAB was a monthly bulletin produced by the Australian Federation of AIDS Organisations. Photo: Jamie Dunbar.

their funders than doing what is right to protect people’s rights and lives. I think it’s important to have independent voices calling out and questioning the AIDS establishment and I try to continue doing that in my way’.

All readily acknowledged that while the AIDS crisis is over in Australia, it is still very present in other parts of the world. The International AIDS Conference in Melbourne will see some of the world’s most inspiring AIDS activists in Australia. Paul Kidd is hopeful that the conference will re-invigorate Australian activists. ‘I think the AIDS conference will be an energising force for HIV activism in Australia,’ he says. ‘I hope it will generate some anger and some willingness to challenge the status quo. It will also help local people see where they fit in the global picture, and maybe contextualise the local challenges and local complacencies in terms of a broader picture.’

**Dr Abigail Groves is a freelance writer and a former Policy Analyst at AFAO.**

# Are we victims of our own success? Addressing the gaps in Australia's enabling environment<sup>1</sup>

By **Sally Cameron**

The trajectory of social values is not linear ... progress is not assured.<sup>2</sup>

Arguments for an enabling environment are not simply about addressing human rights or demonstrating a fine moral compass. They are pragmatic<sup>3</sup> because effective HIV strategy requires inclusivity and 'buy-in' from affected communities.

We started well. The emerging public health crisis (known first as GRID, then AIDS and eventually HIV) galvanised affected populations. It was a community crisis.

Gay men, people living with HIV, sex workers and people who inject drugs organised. Some brave individuals outed themselves – as having HIV, as gay, as a sex worker or as someone who injects drugs ... and by putting a face to the 'name', they humanised the epidemic, and owned it. Communities were active and adamant. Medical and nursing staff risked their own health as well as social judgement.<sup>4</sup> And by some stroke of great good fortune, our governments were interested and (mostly) brave.

In the absence of effective medical interventions, attention turned to the social and legislative factors driving HIV stigma and increasing risk of HIV transmission. A new phrase was coined: the 'enabling environment'. It described the necessity of a supportive legal and policy framework required if HIV education and related public health measures were to work. Those at risk of HIV infection and those living with HIV must be engaged in the HIV response. As it turns out, attention to the 'enabling environment' has proven a concept fundamental to the success of Australia's HIV response.

In early 1990, the Intergovernmental Committee on AIDS established a Legal Working Party to review legislation impacting HIV/AIDS and make recommendations for law reform. Their report, including 89 recommendations for reform of diverse laws<sup>5</sup>, was considered a blueprint for national law reform. While acknowledging that different jurisdictions would need to consider local needs and priorities, both the Intergovernmental Committee on AIDS and the Australian Health Ministers Advisory Council unanimously endorsed the report and its recommendations. Australia's approach to HIV became an international model, and accolades followed, including invitations to Australian jurists to develop international guidelines on a human rights-based approach to HIV.<sup>6</sup>

## Reform slows

The introduction of antiretroviral therapy (ART) in the mid-90s facilitated a shift in focus to medical interventions: HIV was treatable. Next, effective treatments triggered a reconceptualisation of HIV as a chronic manageable condition, and we started to ponder the implications of living with HIV long term. Recently we've focused on (arguing about) the importance of increasing HIV testing and early diagnosis, early treatment initiation and treatment as prevention.

While treatment advances are inarguably wonderful, they have meant that HIV is no longer considered a community crisis requiring radical

legal and policy interventions. Lack of political will is compounded by the unintended consequences of a great deal of great policy analysis and law reform that has delivered impressive results. So too the HIV prevention efforts of peer organisations of sex workers, people who use injecting drugs and their allies has proven so effective that there is no HIV 'crisis' in these populations. We've leveraged some fundamental reforms in Australian law and policy, and consequently facilitated a shift in Australian social values and norms: a shift that has greatly improved the lives of many in affected populations. At this point, do we really need to take on the hard stuff?

Successive Australian national HIV strategies have lauded the enabling environment and the importance of legal and human rights issues, however, they are no longer priorities. Although included in the strategy, they are linked only to broad not specific 'priority actions' or 'implementation strategies'? Despite sustained advocacy by some (more than others), the more contentious issues of law reform have been adrift for some time.

## Discrimination

Australian anti-discrimination law is unrecognisable when compared to the legal landscape of the early 1980s. State and federal law make it unlawful to discriminate against any person with HIV or any person thought to have HIV. Under state law, it is also unlawful to discriminate against people on the grounds of sexuality (variously described in different jurisdictions), and gender identity (also variously described) in most instances. Recent reform of Commonwealth anti-discrimination law also makes

discrimination unlawful on the grounds of sexual orientation, gender identity and (a first in the world) intersex status.

Anti-discrimination protections extend beyond 'anti-discrimination law'. In 2008 the Australian Government introduced legislation to remove discrimination affecting same-sex couples and their children from 85 Commonwealth laws. These included changes to tax, superannuation, social security, Medicare and the Pharmaceutical Benefits Scheme, aged care, child support, immigration, citizenship and veterans' affairs.

Despite such tangible achievements, real gaps remain: notably, anti-discrimination law exemptions allowing religious organisations to discriminate against individuals on the grounds of sexual orientation and gender identity, including in employment and provision of services. These exemptions are particularly galling given many religious organisations now provide services previously provided by Commonwealth agencies. There is also the seemingly intractable thorn in the side: federal marriage law precluding same-sex marriage.

People with a history of injecting drug use are completely locked out of anti-discrimination complaint mechanisms despite stigma and discrimination against people who inject drugs being 'pervasive and entrenched'<sup>7</sup>, including in relation to access to health care<sup>8</sup>.

Anti-discrimination laws have largely failed to address discrimination against sex workers. Sex work related anti-discrimination laws exist in the ACT, Queensland, Tasmania and Victoria, and while it's a start, those laws are narrowly defined and their application limited. In other states, anti-discrimination laws provide no protection.<sup>9</sup>

### Criminal laws

By 1997, laws regulating or criminalising gay sex had been repealed in all Australian states and territories, although it must be noted that the last government to fall (yes,

you Tasmania) had to be dragged kicking and screaming to the United Nations Human Rights Committee (1994) with a three year lag before state legislation was introduced.<sup>10</sup> Age of consent for sexual activity varies across seven of Australia's eight state jurisdictions (either age 16 or 17) but is otherwise uniform across heterosexual/homosexual practice. Queensland remains the notable exception, maintaining a lower age of consent for heterosexual sex (16 years) than sex between men (18 years).

Needle and syringe programs have proven extremely effective, with an estimated 32,000 HIV infections averted, and net financial cost savings exceeding a billion dollars between 2000 and 2009.<sup>11</sup> Yet, incredibly, peer distribution of clean injecting equipment (both common and effective) remains illegal in most states. Laws criminalising injecting drug use in all states and territories exacerbate risk of harm as drug source and quality is frequently unknown, and injecting often occurs in covert environments where injecting is hurried and (crucially for HIV) clean equipment is not available. Peer-led organisations face an uphill battle implementing HIV prevention measures in an environment where the target group is criminalised, ostensibly driving people who inject drugs away from mainstream services.

The peculiar regulation of sex work across Australia includes decriminalised, licensed and criminalised approaches, with no two of the eight jurisdictions the same. Things seemed to be looking up when in 1979, the NSW Government decriminalised sex work.<sup>12,13</sup> Research has consistently shown that decriminalisation has facilitated health promotion<sup>14</sup>, improved occupational health and safety<sup>15</sup>, and eradicated police corruption<sup>16</sup>. It has not increased the incidence of sex work in NSW<sup>17</sup>, or led to greater numbers of sex workers compared to states where similar sex work practice is illegal<sup>18,19</sup>. By comparison, licensing has proven

expensive for governments and business<sup>20</sup>, and created a two-tiered system of legal and illegal workers, with illegal workers wary of public health services<sup>21</sup>. Criminalisation drives sex work underground, reducing access to health and other social supports and impeding outreach. It increases risk of STIs for sex workers and clients as it reduces sex workers' capacity to exercise control over their work.<sup>22</sup> Police continue to use condoms as evidence that illegal sex work has occurred: a slap in the face to HIV prevention strategies. Notably, criminalisation has not eradicated criminalised practices.<sup>23</sup> Yet, despite the much researched health benefits of decriminalisation, no other state or territory government has moved to a decriminalised model, and the NSW model has recently come under renewed threat.<sup>24</sup>

### Criminalisation of HIV

All Australian states and territories have criminal laws that can be applied to cases of HIV transmission or exposure through sex. Such cases have been reserved for instances where the accused is alleged to have failed to disclose their HIV status before sex: effectively criminalising sex without disclosure – not HIV transmission per se, as many cases have involved only the risk of HIV transmission (exposure) without HIV transmission occurring.

There are 40 (known) prosecutions: not many given the more than 32,000 HIV diagnoses that have been made in Australia to date<sup>25,26</sup>, but puzzling given that in many instances, there seems little to differentiate these cases from many of the 1000 new HIV infections that occur through sex each year. Cases are varied: a single or multiple sexual encounter(s); short liaisons or long term relationships; recent encounters or those that occurred long before trial.

Prosecutions undermine the enabling environment because they negate public health messages of mutual responsibility for safe sex practice. They create a false expectation that HIV-positive people will disclose<sup>27</sup>, and suggest

people can rely on disclosure as a core safe sex practice. There is no evidence at all that HIV-related prosecutions facilitate disclosure of HIV status prior to sex or decrease risk taking. To the contrary, almost half (45%) of those surveyed for *HIV Futures 7* said they were concerned about disclosing their HIV status prior to sex because of the law.<sup>28</sup> Furthermore, disclosure has been shown to decrease the likelihood of condom use<sup>29</sup>, greatly increasing HIV risk given some 30 percent of new HIV infections among men who have sex with men are the result of sex with men who believe themselves to be HIV-negative<sup>30</sup>. The criminalisation of HIV is particularly frustrating given that public health regulations offer remedies that can be tailored to the complexities of individual cases where a person is putting others at risk.

### Health systems

Australia is fortunate to have a Medicare system (often) providing access to free or affordable medical services, a Pharmaceutical Benefits Scheme which heavily subsidises the cost of medication, and a social security safety net which further reduces the price of medication for those on limited incomes. Those particularly concerned about issues of privacy, can access sexual health clinics that are able to offer HIV testing without requiring disclosure of a name or address.

Still, laws and regulation continue to undermine effective HIV strategy. The cost of HIV treatments and treatment co-payments remain a major issue for many people living with HIV. Further, dispensing restrictions mean that frequently medication can only be collected from hospital pharmacies during business hours: an onerous requirement for many in terms of travel and managing work commitments.

In some states, public health laws require that sex workers undergo regular sexual health screening and prevent people working while infected with an STI. The unfortunate consequences of such laws were borne

out in massive negative media coverage of a 2011 ACT case in which a man was charged for undertaking sex work while infected with an STI (HIV), despite no suggestion that he placed any clients at risk of HIV infection (hence no further charges were laid). Australian research suggests that mandatory testing is expensive, invasive, unnecessary, and without benefit to the individual. Mandatory testing fails to reach the intended target group, draws testing resources away from high risk populations, and does not reduce HIV infection rates.<sup>31,32,33</sup>

A significant proportion of the Australian prison population is incarcerated for drug related offences. In turn, 'having ever been in prison' is identified as an independent risk factor for hepatitis C infection<sup>34</sup> because unsafe injecting practices occur in prisons<sup>35</sup>, yet clean injecting equipment is not available in Australian prisons. Despite being announced in 2012, Australia's first prison syringe program (in the ACT) is yet to commence operation.<sup>36</sup>

### Conclusion

Advocacy for a stronger legal and policy framework is not easy or without risks. Agencies have been defunded for pushing their politicised agenda 'too hard'. Governments too fear an electoral backlash, and not without reason. Still greater effort is required to extend our enabling environment to deliver greater successes in HIV prevention, care and support. Without constant vigilance, hard won victories can quickly be taken away ... and there is yet more to be done.

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# Sex work legislation stands in the way of Australia's commitments: decriminalisation for sex workers health, safety and rights

By **Janelle Fawkes**

## Australia's commitment

Australia is a signatory to the 2011 United Nations Political Declaration (UNPD) on HIV and AIDS. By signing the declaration, Australia has committed to protecting and promoting human rights and the elimination of stigma and discrimination for people living with HIV and prioritised communities (including sex workers) as a 'critical element in combating the global HIV epidemic'<sup>1</sup> and achieving the UNPD targets.

The declaration also commits Australia to action to achieve this, including 'intensify[ing] national efforts to create enabling legal, social and policy frameworks'.<sup>2</sup>

## What is an enabling legal, social and policy framework for sex workers?

### We know what works

Within Australia most laws regulating sex work are state or territory based. Each jurisdiction has taken a different approach, ranging from criminalisation to licensing models to decriminalisation in NSW. As a result we are well placed to understand the impact of different legal frameworks on sex work, sex workers and HIV. The complex matrix of laws combine with varying policing practices and a variety of other impacting laws including public health and anti-discrimination legislation.

Decriminalisation is the legal framework that sex workers and sex worker civil society or community-based organisations recommend as the best practice model of sex work legislation. This recommendation is the result of

many years of analysis, review of the available evidence – and perhaps most importantly – the lived experience of sex workers working within different legal frameworks. Decriminalisation is also recognised as promoting and achieving high levels of compliance and being a low cost model to maintain. The additional benefit is that it does not divert policing resources away from crime prevention.

New Zealand and New South Wales in Australia are the only two locations globally where versions of decriminalisation have been introduced. New South Wales introduced decriminalisation in 1995 and New Zealand in 2003. Both jurisdictions have provided considerable evidence to inform our understandings of how legal frameworks can provide an enabling environment. Decriminalisation of sex work in NSW has demonstrated it is the most effective legal framework for supporting HIV prevention for sex workers and achieving public health objectives.<sup>3,4</sup> A comparative study by Harcourt, et al.<sup>5</sup> looked at HIV and STI prevention with sex workers across three jurisdictions, each with a different model of regulation. The study demonstrated that sex workers within a decriminalised setting maintained an extremely high level of condom use, extremely low rates of HIV and STIs, and had access to well resourced peer education.

There is also evidence demonstrating decriminalisation provides improved occupational, health and safety for sex workers<sup>6</sup> and contributes to improved human rights<sup>7</sup>. The *Sixth National HIV Strategy 2010–2013* refers to research that suggests within a 'decriminalised

and deregulated legislative framework sex workers have increased control over their work and are able to achieve similar or better health outcomes without the expense and invasiveness of mandatory testing.'<sup>8</sup>

Whilst laws alone will not eliminate stigma and discrimination, decriminalisation has shown strong signs of creating an environment where sex workers are able to address discriminatory practices. Where in place, anti-discrimination legislation that specifically includes sex workers sends a strong message to the community that discrimination against sex workers is unacceptable, promotes social inclusion, and supports sex workers' own campaigns around access to social and legal justice.

The theory that decriminalisation results in the expansion of the sex industry is refuted by evidence based research. In New Zealand data from prior to decriminalisation, compared to data measured at the five-year review stage, shows the size of the sex industry in New Zealand has not increased as a result of decriminalisation.<sup>9</sup> This was also a finding of the Australian study in NSW.<sup>10</sup>

## It is widely recognised that decriminalisation is the best legal framework to support HIV responses

The 2010 UNAIDS Report on the Global AIDS Epidemic states that 'countries should now take action to decriminalize sex workers' and the 2012 Global Commission on HIV and the Law recommends decriminalisation of sex work. The United Nations



**Above:** Sex workers protesting for an end to discrimination. Photo: Zahra Stardust.

Population Fund, United Nations Development Fund and UNAIDS all support the decriminalisation of sex work and note that legal empowerment of sex worker communities underpins effective HIV responses.<sup>11</sup> United Nations Secretary General Ban Ki-Moon called for change in countries where discrimination against sex workers remains legal.<sup>12</sup>

### **We know what doesn't work**

Evidence from Victoria and Queensland demonstrates that licensing models have consistently failed in Australia, and that licensing is ineffective, expensive and unworkable. A licensing model inherently creates a two-tiered industry; the minority who can comply with the excessive regulations and the majority that cannot and are therefore considered 'illegal'.<sup>13</sup> The illegal sector remains under the regulation of police even though Royal Commissions have demonstrated high levels of corruption when police are the regulators of the sex industry.<sup>14</sup>

The Prostitution Licensing Board of Queensland recognises in its annual reports that in more than ten years only 26 brothels have been licensed, at a cost of several million dollars to taxpayers.<sup>15,16</sup> The concept sold to the community that brothel licensing fees would cover the operating costs of the regulatory bodies has never been achieved. While legal sex industry businesses are few and far between in Queensland, individual sex workers are prevented from working in pairs, significantly reducing the ability to work independently. Similarly, in Victoria independent sex workers face significant barriers to operate from their own homes or even separate in-call spaces.

Across Australia street based sex work continues, yet this sector of our community (approximately 5% of all sex work) is heavily criminalised and targeted by police. Condoms continue to be used as evidence in South Australia and Western Australia, and recent statistics from the Victorian Sentencing Advisory Council show

in 2010–12 the highest number of criminal charges against women in Victoria were for street based sex work related charges.<sup>17</sup>

Unfortunately, at a time when significant sex workers campaigns are calling for decriminalisation for our health and safety, we are experiencing a backlash by a school of feminism that conceptualises all sex work as violence against women (also ignoring the gender diversity of sex workers). This wave of sex work abolitionists have consistently ignored the voices of sex workers and progressed a campaign for the Swedish laws (sometimes incorrectly referred to as the Nordic model). Introduced into Sweden in 1999 and simplistically referred to as the criminalisation of the clients of sex workers, the model is in fact a complex set of laws that criminalise many aspects of a sex worker's experience, including supporting partners and children, and the leasing of accommodation to sex workers. These laws significantly undermine the ability to work and are not supported by sex workers.<sup>18</sup>

## Human Rights

Australia's Sixth National HIV Strategy names the protection of human rights to be essential to the effective protection of public health.<sup>19</sup> Sex workers universally advocate for the decriminalisation of sex work, identifying the criminalisation of sex work, sex workers, our workplaces or our clients as approaches that undermine sex workers' human rights and ability to work safely.

Through the Global Network of Sex Work Projects (NSWP) sex workers have agreed to a 'Sex Work, human rights and the law consensus statement' consisting of eight rights. They are the right to: associate and organise; be protected by the law; be free from violence; be free from discrimination; privacy, and freedom from arbitrary interference; health; to move and migrate; and to work and free choice of employment.<sup>20</sup> However, for sex workers in many parts of Australia and our region, there are many examples of laws that undermine these basic human rights and create significant barriers to us working safely. Ironically they are too often misguided attempts to protect sex workers or the community, which fail dismally at both as well as undermining HIV prevention efforts.

This year the Global Fund, a major donor supporting country-level HIV responses, moves to the next phase of its 2012–16 strategy which includes major policy and funding approach changes to ensure human rights are positioned as critical to responding to HIV. The changes aim to integrate human rights into countries' HIV programs, increase investment in programs that address human rights and ensure the Global Fund does not support programs that undermine human rights. As critical enablers to

meet these aims, countries are required to both 'conduct an analysis of the human rights and legal environment (including laws, law enforcement practices and access to justice by those affected by HIV)' and consult with key affected populations, including sex workers, through meaningful input into proposals.

## Well documented yet not progressed

The last decade could be described as a period of strong advocacy, but no progress in achieving enabling environments and human rights for sex workers in Australia. This statement fails to represent the many sex workers who have dedicated their time, expertise, passion and commitment to contributing to law reviews, briefings, hearings and many other mechanisms that should have resulted in full decriminalisation being recognised and introduced throughout Australia. However, sex worker advocates' experience of these mechanisms is that they have not functioned transparently, and were not accountable to the people most likely to be directly impacted as the key stakeholders: sex workers. In too many cases to cover here, sex workers have been silenced, ignored, excluded or dismissed from policy development.

So while there is significant evidence, collected over a period of more than ten years, unfortunately evidence is not what is driving the direction of legal frameworks on these issues. Moral, religious and sex work abolitionist voices seem to have drowned out Australia's commitment to progress this area and the importance of progressing these issues in consultation with sex workers in line with Australia's partnership approach seems to have completely faltered.

## Looking forward

The 'Stepping up the Pace' 20th International AIDS Conference (AIDS 2014) profiles these issues for sex workers, and Australia's actions against these commitments will be under the spotlight. Australia's Seventh National HIV Strategy is likely to be released in time for the event and provides an opportunity for a recommitment to action on the creating of enabling legal frameworks. This will not happen without a paradigm shift that makes the integration of human rights and HIV into policy more than rhetoric.

The work of the Commonwealth Ministerial Advisory Committee on BBV and STIs (MACBBVS) Legal and Discrimination Working (LDW) Group has contributed to the start of this process in the development of a suite of seven papers including key issues and recommendations, yet there remains no mechanism through which to progress this critical work.<sup>21</sup>

In 2014 Australia stands at a threshold in relation to HIV and human rights. The sex worker community is clear on what equates to enabling legal, social and policy frameworks for sex workers – with strong research, clinical evidence and the lived experiences of sex workers showing decriminalisation is the legal framework that enables an effective HIV response for sex workers – what we call for now is the long awaited commitment from government.

Decriminalisation for sex workers health, safety and rights.

**Janelle Fawkes is Chief Executive Officer, Scarlet Alliance, Australian Sex Workers Association.**

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Sex workers universally advocate for the decriminalisation of sex work, identifying the criminalisation of sex work, sex workers, our workplaces or our clients as approaches that undermine sex workers' human rights and ability to work safely.

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# ENDING HIV

Everything has changed. Advances in HIV treatment offer improved health benefits and the potential to dramatically reduce the risk of HIV transmission among gay men by 2020 if we:



Get tested at least twice a year. To decrease undiagnosed infections, to increase access to treatments, more of us need to know our HIV status earlier.

Poz guys – advances in HIV treatment offer improved health benefits and the potential to dramatically reduce the risk of passing on HIV.

By testing more often, by treating earlier and by continuing to stay safe, we can drive new infections among gay men down by 80% by 2020.



**ENDINGHIV.ORG.AU**

# Australia, migration and HIV: an evolving policy landscape

By **Linda Forbes and Michael Frommer**

Planning for AIDS 2014 in Melbourne, Australia, has focused attention on how people with HIV navigate Australia's complex migration system. There is a perception that Australia tests people for HIV with the aim of banning the entry of HIV-positive people. While this is not the policy rationale for testing, this perception nevertheless can lead to alienation among potential residents, and perpetuate HIV-related stigma among new migrants and the Australian community more broadly.

## HIV and the Australian migration process

All people aged 15 years or more seeking permanent visas for Australia are subject to compulsory screening for HIV. Under Australia's migration 'health requirement', anticipated future costs associated with any health condition or disability are assessed – including the cost of HIV antiretrovirals. Migrants have immediate access to subsidised health care and medicines in Australia and the rationale for the Health Requirement is stated to be economic – aimed at ensuring that migration does not place undue pressure on public health costs.

As the lifetime cost of providing HIV antiretrovirals to a person inevitably

exceeds the threshold for passing the Health Requirement – currently AUD\$40,000 – prospective residents with HIV generally fail the Health Requirement in the first instance.

While waiver is available for some visa categories, waiver requires provision of supporting evidence, including medical evidence and evidence regarding the potential fiscal benefit the applicant may bring to Australia. Waiver is, of course, of only limited relevance given that waiver is only available for a few specified visa types and, for those who can seek waiver, people with means are advantaged over people without the capacity and the finances to organise evidence and/or legal advice.

Proposed reforms to the Health Requirement whereby applicants' potential economic contributions would offset future healthcare cost assessments are welcome. However, such changes would represent a limited reform given the challenges associated with providing evidence of the economic contribution an individual applicant would bring to Australia.

## How to make migration policy fairer

Health Requirement assessments regarding HIV pose real and perceived

barriers for people with HIV seeking Australian residence. The economic rationale for the Health Requirement is lost in the policy's complexity and is not generally understood. The perception of prospective migrants – and of the Australian community and international commentators – is that Australia screens prospective migrants for HIV due to a desire "keep them out".

The perception that HIV-positive migrants and their families are not welcome in Australia can feed perceptions that migrants from countries with high HIV prevalence are vectors for disease. This stigmatises people with HIV within migrant communities – with HIV-positive people labelled by some as bringing shame on their community – and feeds HIV-related stigma in the wider Australian community. This stigma undermines affected migrant communities' engagement in the development of HIV prevention, care and support strategies targeting communities of people from high HIV-prevalence countries.

Reform of Australian migration policy is required to bring Australia into line with international human rights standards and public health best practice. Australia has ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD); however, as the *Migration Act 1958* is exempt from the application of the *Disability Discrimination Act 1992*, the legal framework, perversely, facilitates discrimination against people with HIV.

There should be no compulsory HIV-testing of people applying for Australian residence. Mandatory testing for HIV should be replaced

The economic rationale for the Health Requirement is lost in the policy's complexity and is not generally understood. The perception of prospective migrants – and of the Australian community and international commentators – is that Australia screens prospective migrants for HIV due to a desire "keep them out". Mandatory testing for HIV should be replaced with voluntary testing of applicants and of permanent visa holders upon arrival in Australia.

## AUSTRALIA'S HEALTH REQUIREMENT FOR PERMANENT VISA APPLICANTS

### The process

All permanent visa applicants of 15 years of age or over are required to take an HIV test. Applicants under 15 are also required to be tested if being adopted, there is a history of blood transfusions or other clinical indications.

#### Positive result

The Department of Immigration will estimate whether the future costs in relation to the person's HIV status will exceed AUD\$40,000 over their lifetime.

### HIV test

#### Negative result

Applicant must still meet other aspects of visa Health Requirement, including cost assessments in relation to any other chronic health conditions or disabilities.

#### Significant cost

An assessment is made of the person's potential health care costs associated with HIV over their lifetime. This is based on the likely costs of providing treatment/community services to a "hypothetical person" with the same condition of the same severity as the applicant. The current "significant cost" threshold is AUD\$40,000. Lifetime cost of HIV antiretrovirals will always exceed this threshold, so HIV-positive applicants inevitably fail the Health Requirement, unless waiver is available.

#### Is waiver available to all HIV-positive applicants?

No – waiver of the Health Requirement is currently only available for permanent visa sub-classes in the following categories: Partner; Child; Adoption; Humanitarian; and specified employer sponsored. If waiver is not available for a particular visa sub-class, the applicant fails the Health Requirement and they are refused a visa.

#### What is taken into account for waiver?

Where waiver is available the Department of Immigration will consider whether the assessed costs are "undue". This involves consideration of whether the cost to the community or prejudice to access of Australian citizens and permanent residents to healthcare and community services in short supply, is unlikely to be "undue". Evidence of any compassionate circumstances will be considered, as will evidence of the extent to which the applicant and their family are able to mitigate potential costs or "prejudice to access" identified by the Department of Immigration factors may include the family's potential contribution.

#### Will a person whose costs are not considered to be "undue" have the health requirement waived?

Yes.

#### Will a person whose costs have been assessed as "undue" be able to migrate to Australia?

No, they will be refused waiver and their visa application will be rejected.

with voluntary testing of applicants and of permanent visa holders upon arrival in Australia, with appropriate counselling and support provided to all applicants who undertake HIV testing for migration purposes. It is now time for long overdue migration reform.

Linda Forbes is Manager, Policy and Communications, at AFAO. Michael Frommer is Policy Analyst at AFAO.

# HIV AUSTRALIA

HIV Australia is available online with additional content.

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

A digital retrospective of HIV health promotion materials, curated by L. K. Chan and Raymond Donovan, will be on display in the G'Day Zone at AIDS 2014.

A catalogue accompanying the exhibition is available for download in HIV Australia online

# How to spread gay rights beyond the West

By **Dennis Altman**

While the march of gay rights continues across the West, in parts of the world they are going backwards, with states hardening their repression of people on the basis of their sexuality, writes Dennis Altman.

Currently Ethiopia is tightening its laws against homosexual behaviour, already punishable by up to 15 years imprisonment. It appears the government is following the lead of Uganda and Nigeria, both of which have recently introduced laws increasing the penalties for both homosexual behaviour and support for any “advocacy” of recognition of same-sex identities or behaviour.

Similar hardening of repression of people for homosexual and transgender identities appears to be increasing across Africa. A recent documentary about Cameroon, *Born this Way*, highlights the violence and persecution against anyone perceived as not conforming to sexual or gender norms. Lest we think the repression is confined to men, that documentary highlights the fear of imprisonment and “corrective rape” faced by women assumed to be lesbian.

Recent laws in Russia, supported by President Vladimir Putin, which seek to penalise “propaganda” of homosexuality, generally with the intent of “protecting” minors, have been used as the excuse for right-wing thugs to engage in vigilante actions against homosexuals, depicted in a recent Foreign Correspondent program.

These laws became the focus of international attention because of the Winter Olympics in Sochi, and Russia’s increasingly belligerent attacks on “Western values”, using the language of “traditional values” and the “traditional family” to rally international support.

Similar arguments remain central in the rhetoric of governments across the

Islamic world, including countries in our region. Indeed, Pakistan and Malaysia are among the most vigorous opponents of any recognition of “sexual rights”, and the recurring prosecution of Anwar Ibrahim for alleged sodomy is a reminder that such attacks are often politically motivated.

Let us be clear: these are not arguments about whether or not homosexuals can adopt children or have the right to be married.

In Nigeria men have been publicly whipped for homosexuality while crowds called for their execution. In Iran it is known that homosexuals have been executed, although ironically gender transitions are legal. Violence against transgender people is widespread through much of the world.

At the same time there is a remarkable shift in attitudes in most of the Western world, symbolised by the growing number of jurisdictions that recognise same-sex marriage (including several conservative American states), and strong official statements against homophobia in a number of Latin American countries.

Both the United Nations Human Rights Council and Secretary General Ban Ki-moon have asserted that human rights should apply without distinction on the basis of sexual orientation or gender identity.

Central to the rhetoric of countries as seemingly dissimilar as Russia, Pakistan and Zimbabwe is the claim that homosexuality is a western import, designed to weaken traditional cultures and religions. Thus the ironic situation

arises that most of Britain’s former colonies retain anti-sodomy laws in the name of their cultural heritage, ignoring the fact that these laws are in fact the legacy of the colonial era.

The growth of state-sanctioned homophobia is related both to religious fundamentalism and nationalist assertion. When the Indian Supreme Court recently upheld British-era sodomy laws it was noted that this was the only issue on which leaders from all religions could agree.

The support of leaders such as US president Barack Obama and UK Prime Minister David Cameron for gay rights has ironically reinforced those political leaders who use the issue to mobilise nationalist fervour by scapegoating people who can be linked to foreign influence.

Both the current and previous Australian governments have worked quietly to make clear their disapproval of persecution on grounds of sexuality. In this they are unfortunately ahead of most of Australia’s NGOs, who have been largely disinterested in the issue.

Other than specific gay community organisations, only Amnesty has given much prominence to this issue. Yet sexual rights, and the debate around protection of people vulnerable because of their sexuality or gender identity, apply to a number of countries in our region, including Papua New Guinea.

The Senate inquiry into asylum seeker policies established that some people seeking asylum because of fears of persecution for their sexuality now fear further persecution when they are sent to Manus Island.

It is tempting to express outrage at abuses done in the name of protecting morality, but indignation is not the basis for good policy. The recent decision of the US administration to

cut aid to Uganda's health sector will mean some people will lose access to vital therapies; it will do nothing to weaken President Yoweri Museveni's government. Some European governments have been more strategic, redirecting the funds to NGOs working in the country.

Sexuality has become a polarising issue in the international arena, and both sides are tempted to play to their domestic audiences rather than consider the human costs.

In the lead up to AIDS 2014, Oxfam and La Trobe University's Institute for Human Security and Social Change hosted a pre-conference panel discussion on 17 July 2014 entitled: 'Let's Talk: Sexual Rights, HIV and Development'. The purpose of the evening was to encourage discussion between the HIV and development sectors about the growing global polarisation around sexual rights, in particular the growing persecution of people in many parts of the world on the basis of their sexuality or gender identity.

We need further opportunities such as this for strategic reflection on the best way to promote greater acceptance of sexual diversity in a world where too often sexuality has become a touchstone for fear, prejudice and hatred.

**Dennis Altman is a Professorial Fellow in the Institute for Human Security at La Trobe University.**

**This article was originally published on ABC's The Drum ([www.abc.net.au/news/thedrum](http://www.abc.net.au/news/thedrum)). The original version of the article is available at: [www.abc.net.au/news/2014-03-28/altman-how-to-spread-gay-rights-beyond-the-west/5351556](http://www.abc.net.au/news/2014-03-28/altman-how-to-spread-gay-rights-beyond-the-west/5351556)**

## In memoriam

# TRIBUTES TO VIVIENNE MUNRO

**Vivienne Munro was a pioneer of Australia's early HIV response, much-loved and admired for her contribution to Australia's community response and support for HIV-positive women. Vivienne passed away in May 2014. Below, some of Vivienne's close colleagues and friends pay tribute to her life and work.**

**Vivienne Munro was a courageous pioneering woman living with HIV. In the late 80s, Vivienne set up the first Positive Women's group in Sydney. Vivienne was then instrumental in being the first women-specific peer support worker at ACON (a position which no longer exists). Vivienne was a wonderful advocate to ensure women living with HIV had a voice in the AIDS dialogue.**

In the nineties, Vivienne was the Asia-Pacific regional representative for ICW (International Community for Women Living with HIV/AIDS). In this role, Vivienne worked tirelessly by providing peer support and training for women living with HIV and was a great advocate for the rights of women.

Vivienne's legacy will live on. She will be sadly missed by her children, family friends and colleagues. I, for one, will miss her as we often worked together locally, regionally and internationally, where we inspired each other as well as having fun. Her motivation was always for the care and support of others, particularly women living with HIV.

Bye Vivienne, you were a true hero.

— Bev Greet

**Vivienne Munro was involved in the response to HIV since the 1980s. One of the first women in NSW to be open about her HIV status, she played a key role in the ACON HIV Support Project and the early years of what was then PWA(NSW) (which became PLWHA (NSW)) and then Positive Life NSW.**

Vivienne was involved in setting up HIV support and networks for women in NSW. She also got involved in the international HIV movement, and for a period was involved with the Global Network of People Living with HIV/AIDS. She was on the committee of Positive Life a number of times, serving as Co-Convener and Secretary and contributed to some of its working groups in particular the *Talkabout* Editorial Group.

Vivienne's partner died of HIV before effective treatments arrived. She has two children – Tasman and Larna. Vivienne has been living on the NSW Central Coast for a number of years. A tireless and energetic advocate of people living with HIV, Vivienne made a major contribution to the Australian response to HIV and the support of women living with HIV.

The staff and board of Positive Life NSW extend our condolences to Vivienne's family and loved ones, and our sincere gratitude for her work.

— Positive Live NSW

**The first time I saw Vivienne was in a poster she was part of with five other women and the caption said, 'Some of us are HIV-positive' with a tag line, 'HIV-positive women are women like you'. It was a promotion for the HIV Women's Project in NSW at ACON.**

Then I met Viv and many other women like Bev and Amelia, and it was a turning point for me and had a huge impact on how I took on my new peer support role in SA back in 1998. I commenced my journey of challenging HIV-related stigma and the courage came from their first steps.

— Katherine Leane

**More tributes to Vivienne Munro are included on the AFAO blog at <http://afaotalks.blogspot.com.au>**

# Developing the narrative of HIV-related stigma and discrimination in Papua New Guinea

By **Dr John Rule and Annie McPherson**

This article reports on the experience of Igat Hope, the organisation representing people living with HIV (PLHIV) in Papua New Guinea (PNG), in furthering the understanding of HIV-related stigma and discrimination in PNG. We describe this process as 'developing a narrative' because some of this work has already been completed, some work is currently being done (the research on which we report) and more work is required into the future. Some of this narrative has been discussed many times before, and some is still being written. Other people are also contributing to the ongoing development this narrative, of course; here we report only on the work that we have been part of.

Phase one of the PNG Stigma Index project, supported by funding from the National AIDS Council (NAC) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) in PNG, has been conducted in the Western Highlands and Simbu provinces. The PNG NAC provided funding support to the Igat Hope secretariat and for other associated research costs; UNAIDS supported the project through funding the training programs of the group of people living with HIV who conducted the interviews.

The PNG Stigma Index is significant because it is a project owned by Igat Hope and its membership. In PNG the project has been largely managed by HIV-positive people within the organisation. The project is building community knowledge and engagement of people living with HIV as it proceeds, and is directing attention to the ways in which stigma is being experienced by HIV-positive people in a range of contexts.

This article provides some background to the project, and reports briefly on its findings. In the context of uncertain funding support in PNG, we also note some hopes for the future with regard to this project.

The PNG Stigma Index is significant because it is a project owned by Igat Hope and its membership. In PNG the project has been largely managed by HIV-positive people within the organisation. The project is building community knowledge and engagement of people living with HIV as it proceeds, and is directing attention to the ways in which stigma is being experienced by HIV-positive people in a range of contexts. Sadly, two Igat Hope staff members, who were openly HIV-positive and took carriage of work within the organisation, have died. Ms Helen Samilo, who attended trainings on the implementation of the *People Living With HIV Stigma Index* died in August 2013; Don Liriope who was the Co-Principal Investigator on the project died in March this year. Their deaths are very sad losses.

## Project aims

1. To provide additional data to that which is currently available in PNG and provide evidence-based

information for program planning and interventions in response to HIV-related stigma in PNG.

2. To provide additional data about the ways that stigma and discrimination creates barriers to accessing services and impedes the scaling up of delivery of antiretroviral therapy in PNG.
3. To describe the levels of stigma and discrimination faced by people living with HIV in different provinces.
4. To describe the differing experiences of people living with HIV according to gender, sexuality, sexual expression or gender identity.
5. To determine the situations creating heightened risks for people living with HIV and to identify policy and program responses to reduce this risk.
6. To determine the ways in which the persistence of stigma and discrimination inhibits and undermines effective prevention strategies.

## HIV-related stigma and discrimination in PNG

It is widely acknowledged that HIV-related stigma and discrimination remain barriers to effective prevention, treatment, care and support programs in PNG. There is ample anecdotal evidence that the experience of stigma and discrimination discourages people from presenting for testing, or upon diagnosis not returning for follow-up; stigma and discrimination creates barriers to accessing health services.

*The Systematic Literature Review of HIV and AIDS Research in PNG (2007–2008)* noted that there is

significant reporting of the ways in which people living with HIV have been violently mistreated and shamed, but there were few studies that focused on this experience from the point of view of people living with HIV. The Systematic Literature Review identified studies that reported on stigma and discrimination – where the perspective was that of the health care workers or study respondents, looking at attitudes towards people living with HIV. Few studies sought to examine mistreatment and shaming from the perspective of people living with HIV themselves.<sup>1</sup>

One large-scale study on the experiences of people living with HIV showed that there is limited support for those experiencing stigma and discrimination to pursue their legal rights and that, although there have been some changes in community attitudes, there are still unacceptable percentages of people living with HIV – especially women – reporting verbal and physical abuse. This study identified that there is research in other countries in the region in relation to stigma and challenges for people living with HIV, but the data that is available in PNG needs to be further developed.<sup>2</sup>

Various PNG UNGASS (United Nations General and Special Assembly) Country Progress Reports, successive National HIV Strategies and the *Report of the Commission on AIDS in the Pacific 2009* have all noted that stigma and discrimination impact negatively on controlling the spread of HIV.<sup>3</sup> The *PNG Independent Review Group on HIV/AIDS* heard stories of stigma against HIV-positive people, indicating that stigma continues to be a real barrier to HIV prevention.<sup>4</sup> The report prepared by the review group said that the implementation of the *International People Living With HIV Stigma Index*<sup>5</sup> needed to be finalised and implemented with speed so that findings could be incorporated into program responses.



Don Liriope, far left, Co-principle Investigator on the PNG HIV stigma project, with other members of Igat Hope research team out collecting data in and around Mt. Hagen, PNG. Photo: John Rule.

## In memoriam

**Don Liriope died in Port Moresby General Hospital on 18 March 2014, due to tuberculosis of the liver. Don had lived openly as an HIV-positive person for many years.**

Don was a passionate advocate for the rights of people living with HIV, gay men, men who have sex with men (MSM), and transgender people in Papua New Guinea (PNG).

Don was employed by Igat Hope, PNG's national organisation representing people living with HIV, as the Stigma and Discrimination Project Officer. He was also a founding member and Vice President of Kapul Champions, a community-based organisation established by MSM and transgender people in PNG to represent community interests and contribute to PNG's national HIV response. Don's colleagues loved working with him. He was energetic, passionate and he was able to stand up for what he believed in and was always keen to communicate to others what he felt was right.

Don spoke very clearly about the rights of communities to participate in research and he understood the benefits that research would bring in helping to manage the HIV epidemic in PNG. He understood that people living with HIV needed respect and dignity. He wanted the voices heard. He was not afraid – he would speak directly and convincingly to everyone about his concerns. This meant that Don was known to many people in PNG beyond the HIV sector, and to people in other Pacific Island countries and territories, and in Australia for his advocacy efforts on behalf of people living with HIV.

Don had a great sense of humour, was fun to be with and was able to relate to people of many different levels. Don was savvy. His death is a great loss. We will all miss him.

— John Rule

## Using the International Stigma Index tool

The potential use of the Stigma Index tool was discussed at the first national conference for people living with HIV in PNG in 2009. Helen Samilo, a staff member of Igat Hope, attended a meeting in Bangkok about the international efforts to implement the Stigma Index. The Igat Hope Board supported the creation of a special position within the National Secretariat specifically to implement the Stigma Index in PNG; Don Liriope was employed in this position. In 2010, the second national conference for people living with HIV in PNG endorsed efforts to implement the index in PNG. John Rule was invited by Igat Hope to be the Principal Investigator and to assist in developing the study proposal and ethics application for the National AIDS Council Research Advisory Committee.

The international *People Living With HIV Stigma Index* was seen as a useful instrument to try and apply in the PNG context, although it has always been the view of Igat Hope that the index would need to be adapted and amended for the PNG context. This adaptation was not just to be a matter of translation into relevant language, but would also take into consideration the preparedness of the local communities of people living with HIV to work with the survey instrument. The implementation of the Stigma Index in PNG is also a way of enabling people living with HIV to take a more active role in responding to the HIV epidemic by managing a significant national research project.

## Outcomes from phase one data collection in the Western Highlands and Simbu

Eighty interviews were conducted. Seventy-five respondents indicated that they are sexually active although only twenty of the respondents said they are married or co-habiting with a partner. Over 10% identified as belonging to the category of sex worker and a small

percentage said that they belong to the group men who have sex with men, or identified as gay. Over 70% said that they had been physically assaulted in the previous twelve months because of their HIV status. Over 50% said they had not attended social gatherings because of their HIV status. Being gossiped about was identified as the major problem and nearly 50% of the respondents said they had feelings of being ashamed, guilty or blamed themselves because of their HIV status.

From the interview data it can be said that stigma and discrimination are found in the following settings:

- family and clan
- community and peer networks
- workplaces and health care settings.

Recommendations are tentative, being based on two provinces only, but areas identified where action can be taken include:

- PLHIV networks and support group relationships with communities
- PLHIV network building and peer interaction
- capacity building in health care settings
- further engagement with the legal and para-legal practitioners
- improving stakeholder relationships with HIV-positive communities.

Igat Hope will continue to take the lead on this project, as outlined in the PNG National HIV Strategy. Problems using the Stigma Index tool were identified by the research team (e.g. the instrument only asked questions about events in the previous 12 months). The application of the index as the correct tool to use, in the PNG context, may be reviewed. Igat Hope aims to continue with the project and, through discussion with funders such as the National AIDS Council and UNAIDS in PNG, to determine the best approach to develop understanding of and response to HIV-related stigma and discrimination in PNG.

**Dr John Rule is a Conjoint Associate Lecturer, School of Public Health and Community Medicine, Faculty of Medicine, UNSW and the Principal Investigator on the National AIDS Council approved study: HIV-related Stigma and Discrimination and Human Rights in PNG (ref: RES10-014). Ms Annie McPherson is the Executive Director of Igat Hope, the national organisation representing people living with HIV across PNG. Annie has been working with Igat Hope for over five years, and has provided management oversight for this project within her role as Executive Director.**

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# Walk with me: creating an enabling environment for men of diverse sexualities and transgender people in Papua New Guinea

By **Finn O’Keefe and James Malar**

In Papua New Guinea (PNG), sex between men is criminalised. Many people in the community hold strong views against homosexuality<sup>1</sup> and acts of violence against sexually diverse men and transgender people are common<sup>2</sup>. One recent study examining gender-based violence in PNG and Bangladesh indicated that police and health care providers were two key sources of violence towards sexual minorities.<sup>3</sup>

The threat of criminal sanctions, combined with repressive societal norms and religious beliefs, creates an environment where men who have sex with men and transgender people are highly stigmatised. This results in a level of secrecy around sex which heightens HIV risk and hinders HIV prevention efforts.<sup>4</sup>

## Advocating for change

Kapul Champions, the national network for men of diverse sexualities and transgender people, is working to effect change in PNG. With funding from the Australian Government’s aid program, and technical support from the Australian Federation of AIDS Organisations (AFAO) and Igat Hope (the national network of people living with HIV in PNG), Kapul Champions are advocating for law reform, supporting community mobilisation and promoting initiatives to increase access to health and HIV services in PNG.

Saturday 17 May, 2014 marked the 10th annual International Day Against Homophobia and Transphobia (IDAHOT 2014). For the first time, through an initiative coordinated by Kapul Champions, PNG joined with other countries participating in this global day of action in support of lesbian, gay, bisexual, transgender and intersex (LGBTI) human rights and freedom of expression.

In the weeks leading up to IDAHOT 2014, Kapul Champions launched Walk With Me – Together We Are PNG, a campaign promoting acceptance and celebration of the diversity of sexual orientation and gender identity in PNG. The campaign was designed to fight stigma and discrimination, and launched to become the country’s first ever coordinated IDAHOT activity.

‘Kapul Champions is proud to be representing Papua New Guinea in the global IDAHOT conversation promoting human rights, social inclusion and the freedom from discrimination and stigma, as well as raising awareness about repression and violence toward men of diverse sexualities and transgender people,’ said Manu Peni, President of Kapul Champions.

## ‘I do not discriminate’

The Walk With Me – Together We Are PNG campaign, centers around a poster featuring a Kapul Champions Board member walking hand-in-hand with fellow Papua New Guineans to illustrate that all PNG citizens deserve an equal place in PNG society and community, irrespective of their sexuality or gender. The poster was distributed at community meeting spots, sports clubs, police stations, non-government organisations and government agencies, clinics and hospitals across PNG.

The Walk With Me – Together We Are PNG campaign, centers around a poster featuring a Kapul Champions Board member walking hand-in-hand with fellow Papua New Guineans to illustrate that all PNG citizens deserve an equal place in PNG society and community, irrespective of their sexuality or gender.

The poster was linked to social media to increase the campaign’s visibility and reach. The campaign uses Facebook to create a space for people to express support for the campaign and for diversity in PNG. The campaign invites participation by encouraging community members, government representatives and other development partner stakeholders to share a photo of themselves on Facebook posing with the campaign poster, accompanied by a short message of support. This could be a simple statement such as ‘I do not discriminate’.

The online component of the campaign has helped to spread the central message of support and inclusion. By May 17, when IDAHOT 2014 was held, the PNG Walk With Me Facebook page had 130 members, and numerous photos and messages had been uploaded to the site. Photos were submitted by community members and community leaders, as well as members of parliament, police officials, United Nations and development partners’ staff, National AIDS Council staff, community-based organisations and regional and international supporters.

## ‘We are walking with you’

Importantly, many messages of support have come from ‘every day’ people. Posts on the Facebook page include a hotel chef photographed on his ‘day

off', a librarian from the Institute of National Affairs, police officers, taxi drivers, and tradespeople, all proudly voicing support for diversity and inclusion.

Messages of support on the Facebook page include:

*'We are walking with you'*

*'We don't hate, We Love'*

*'I do not discriminate'*

*'We Air Con Technicians, we do not discriminate!'*

*'Great to be apart of this. one love, one heart. lets walk together.'*

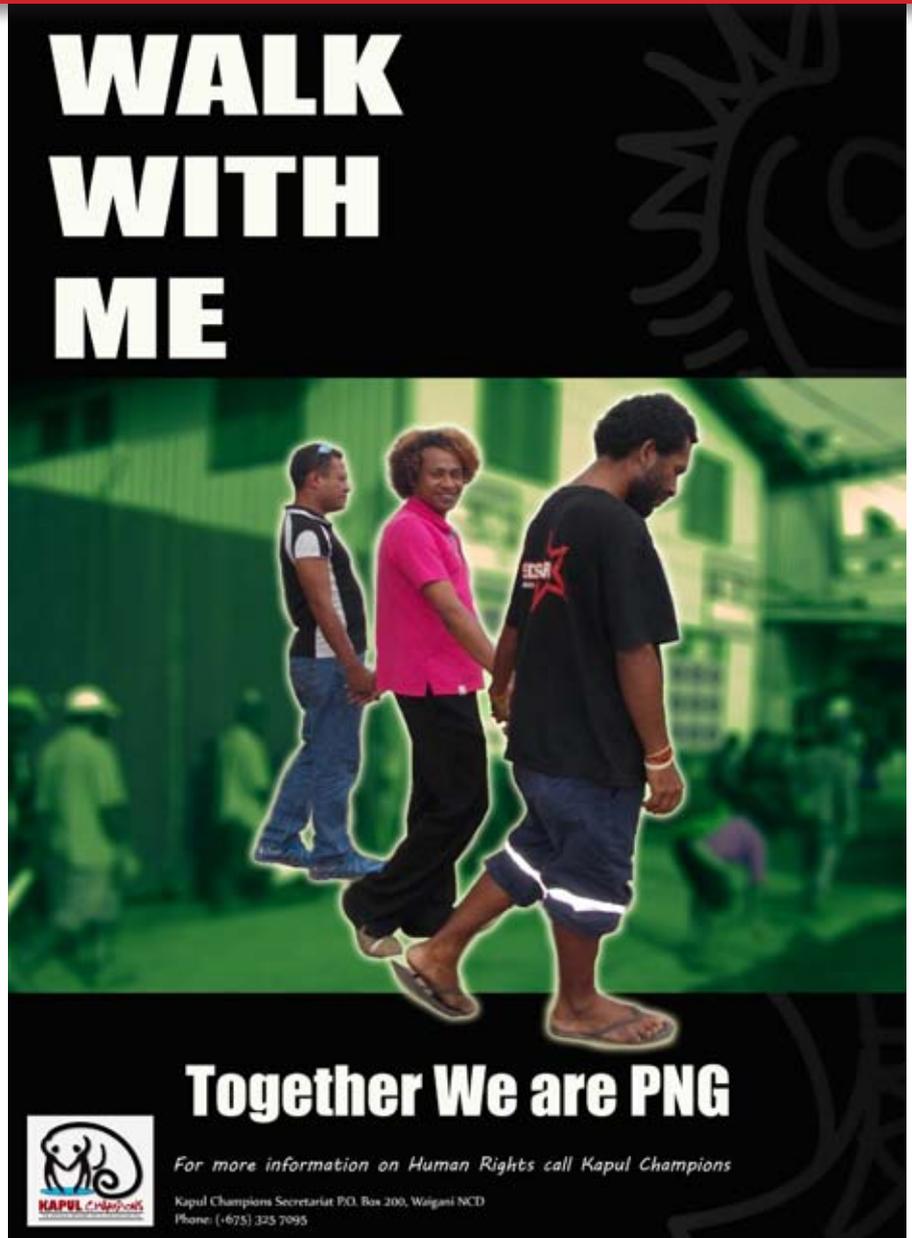
*'A great initiative from Kapul Champions, I support #WalkWithMePNG.'*

These contributions combine to make a strong statement that community support for diversity does exist, and this support can be found among people from all walks of life in the PNG community.

Chris Connelly, AFAO International Program Manager says that this is the first time Kapul Champions has done a public campaign. 'Conversations on sexual orientation and gender identity can be challenging in PNG', he explains. 'With the campaign Kapul Champions has found many willing supporters for the principles of 'Walk With Me – Together We Are PNG'.

Nick Morea-Evera, Senior Program Officer from Kapul Champions, expressed a great sense of sense of achievement in launching the campaign: '2014 is the first year PNG joined the global IDAHOT activities, and it is great for PNG to be among the other 120 countries marking this important day!'

Kapul Champions invite you to show your support by 'liking' the Walk With Me – Together We Are PNG Facebook page, and by following the campaign on Twitter. Add your comments on Facebook, and on Twitter @KapulChampions #WalkWithMePNG to support and celebrate diversity in PNG!



**Above:** The Walk With Me – Together We Are PNG campaign poster depicts a Kapul Champions Board member walking hand-in-hand with fellow Papua New Guineans.

**Finn O'Keefe is Communications Officer at AFAO and an editor of HIV Australia. James Malar is the Engagement and Communications Advisor at AFAO International Program in Bangkok.**

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# Australian support for community HIV responses in PNG: what works, how do we show it, and who will fund it anyway?

By **Tim Leach** and **Dr John Rule**

The National Association of People Living with HIV Australia (NAPWHA), the Australian Federation of AIDS Organisations (AFAO) and Scarlet Alliance have conducted partnerships programs in Papua New Guinea (PNG). NAPWHA has worked with Igat Hope, PNG's People Living With HIV (PLHIV) organisation for over a decade. Scarlet Alliance is currently working in partnership with Friends Frangipani, PNG's national sex worker group, and AFAO has been working closely with Kapul Champions, the recently established network representing men of diverse sexualities and transgender people.

But these are challenging times for the community response in PNG. The Department of Foreign Affairs and Trade (DFAT) is refocusing its work away from service delivery in PNG and its work in HIV is increasingly absorbed into a more generalised health program, reducing the national focus on HIV. At the same time we hear much from Canberra about the need for Australian aid to align more closely with Australia's strategic interests, to prioritise initiatives that stimulate economic activity and that deliver results that can be easily demonstrated and measured against benchmarks. So where does this leave these three community collaborations?

A NAPWHA-sponsored forum was held recently in Sydney to consider these related issues. Representatives from Australian HIV organisations, development workers from a range of Australian agencies, and a few interested individuals, tried to work out how the community HIV response in PNG might be best protected and supported.

This article draws from the insights shared at the forum but the views expressed here are those of the authors.

## Language matters (as if we needed more proof)

Pretty much every story about PNG mentions it is known as the land of the unexpected. And so, as we might have guessed, the epidemic in PNG has involved a few surprises. What began as a generalised epidemic – feared capable of matching the worst of Africa's – suddenly morphed into a concentrated epidemic. Or did it?

Despite an at times unseemly scramble to convert the PNG response into one that addresses a concentrated epidemic, more recent discussions suggest that the epidemic is neither general nor concentrated. It is complex. It is varied depending on location. It is geographically varied. It is changeable over time as circumstances change. It can be impacted by local customs or local events. In fact, it might be said there are multiple epidemics.

The national organisations – Igat Hope, Friends Frangipani and Kapul Champions – will need some language around this. They stake a claim to further financial support – most significantly from DFAT – partly because the epidemic is *not* a general one, but one with particular implications for their constituencies. Friends Frangipani and Kapul Champions both say from time to time that there are higher rates of HIV within their communities, but neither has language around the complexity of the epidemic. Hard data relevant to their communities is very limited, so

their claims of being disproportionately impacted need to be strengthened by reference to other knowledge.

Current debates around language in PNG aren't restricted to the ways in which people describe the epidemic. They also rage about how those communities significantly affected by HIV are to be described. It is common to talk of Most At Risk Populations (MARPs) in PNG, but marginalised groups don't like being described as MARPs, and have said so repeatedly and formally. Not only is the language inaccurate, but it is also experienced as deeply offensive. There is widespread acknowledgement that MARPs is a donor-driven notion, yet it does indeed drive funding decisions so the national organisations will need language around their risk relative to other communities.

Kapul Champions and Friends Frangipani both refer to higher rates of infection within their constituencies, implying some degree of identify that is related to marginalisation and risk of HIV. They say quite often that they have heightened vulnerability to HIV, and Igat Hope rightly claims its constituents are at heightened risk of the negative impacts of HIV – indeed this has been proven through Igat Hope research on HIV-related stigma and discrimination. These notions then of heightened risk and/or vulnerability to HIV and its impacts are important to the organisations and they infer some notion of there being a concentrated epidemic.

So in rejecting the term MARPs how do the constituencies of the three national organisations want to describe

their relationship with HIV? Would they be content to describe themselves as key affected populations (another popular descriptor in PNG)? As marginalised? As vulnerable?

### The fly-in/fly-out model of support

The fly in/fly out (FIFO) model of development support has few friends. It is considered neither cost-effective nor sustainable. But we need a more sophisticated position than 'fly in/fly out doesn't work'. Leaving aside the pejorative nature of the description – which reduces ongoing support to in-country events – FIFO actually *does* work in *some* ways for *some* things.

NAPWHA has compiled a thorough report that reflects on a decade of collaboration with Igat Hope. The report<sup>1</sup> indicates that Igat Hope would have preferred a more permanent NAPWHA presence in PNG, yet despite this, Igat Hope valued many of NAPWHA's efforts, even though they were significantly of a FIFO nature. Scarlet Alliance has stories about how FIFO has actually helped establish Friends Frangipani in ways other models of support could not. If Scarlet Alliance were present in PNG all the time it would risk becoming the default decision-maker for all things related to sex work; its absence makes agencies and organisations in PNG deal with Friends Frangipani and encourages Friends Frangipani to make decisions without constant reference to Scarlet Alliance. Australian community-based organisations (CBOs) have also warned against thinking that supports are only being provided during an in-country technical visit: they may be ongoing,

being provided by a range of people via a range of mediums, perhaps simultaneously.

This is not a defence of the FIFO model. Most people see its weaknesses, including NAPWHA, Scarlet Alliance and AFAO. But in determining what the national organisations need, we will need a more sophisticated analysis of the various modalities of providing technical assistance than 'FIFO doesn't work'. We need to be able to say what does work.

Already we can say things about how important it is to be able to do long-term planning, to build up work over long periods. We can say very positive things about the value of peer-to-peer support.

We need to call for proper evaluation of the community partnership model. NAPWHA has already carried out a substantial evaluative process, including report writing and iterative discussion with Igat Hope and key stakeholders in PNG. NAPWHA's work to date gives us reason to believe that the evaluation will show community partnerships to be effective, and cost effective.

In recent times, DFAT PNG has moved away from funding the Australian CBOs to provide partnership support. Instead DFAT has shown an interest in funding international volunteers to work with the national organisations. While lots of people can tell stories of amazing volunteers in PNG, there is scepticism around the proposed international volunteers as a replacement for support from Australian CBOs. Scarlet Alliance and Friends Frangipani have expressed the view that it is not an

appropriate form of support for Friends Frangipani. NAPWHA has also expressed reservations. The process to replace NAPWHA's technical input with a volunteer in the Igat Hope office began over twelve months ago. To date, there has been no replacement organised by Australian Aid (formerly AusAID) or DFAT. AFAO has had good experiences with volunteers in its other international work but wonders how this will translate to PNG. And all this is occurring against the backdrop of a broader national debate in PNG around the role and meaning of volunteering. Clearly, if the volunteer placement program is to proceed, it should be carefully evaluated.

### Everybody loves advocacy, but ...

What do we mean by advocacy in the current context? Where there is no hope of legal reform, as is the case currently in PNG, what are we suggesting the organisations actually advocate *for*? There are, currently, few champions of law reform in PNG in positions of power. Indeed only a single MP (from East New Britain) has made recent statements likely to give any heart at all to the national organisations.

We say the organisations should be advocating for 'a seat at the table', but is there even a table in PNG? The abject failure of the National AIDS Council and the government to create these collaborative decision-making forums causes us to wonder at what table we want the organisations to get a place.

Scarlet Alliance has some stories of successful local-level advocacy and it is important that these be collected and shared. Perhaps we need to shift our advocacy focus towards these smaller, more local goals.

And expectations around the advocacy capacity of the national organisations need always to be grounded in an understanding of the abject poverty characterising the lives of so many of the organisations' volunteers and constituents. They need to take account

They need to take account of the inadequacy of the national health system, and acknowledge that many of those leading the advocacy efforts of the national organisations will experience ill health and poor care.

of the inadequacy of the national health system, and acknowledge that many of those leading the advocacy efforts of the national organisations will experience ill health and poor care.

### The place of the national organisations

There is general acceptance within PNG of the need for the national organisations. But beyond this, what level of support exists?

When NAPWHA's activities in PNG were defunded, it asked DFAT to give these resources directly to Igat Hope, so that Igat Hope could source its own technical advice. DFAT instead sought to replace NAPWHA with an international volunteer. Yet NAPWHA's program concluded in 2012 and there is still no volunteer. That's about \$200,000 and counting that *hasn't* gone to Igat Hope as technical assistance. In view of this lack of follow-up by DFAT in-country, NAPWHA is seriously concerned for the viability of the organisation.

The commitment to the volunteer program is, happily, an indication that DFAT will continue to support the national organisations. There have been other welcome indications as well, and these are all extremely important, as of all the donor agencies in PNG, DFAT has been the national organisations' most reliable and generous funder. DFAT is likely to remain critically important. There is no chance that the government of PNG will fund the national organisations. There is next to no chance that other donors will fund the organisations in the way they need to be funded. Donors love a flashy project, but no agency other than DFAT has shown a preparedness to fund the core costs these organisations must meet if they are to function effectively.

DFAT PNG will need to be supported here as it argues for continued support of the national organisations. The national organisations are very precarious, and the Key Affected

Population's (KAPs) response is similarly fragile. To protect DFAT's past investment in this KAPs response, it will need to keep funding the national organisations, and it will need to do so generously.

But in all likelihood the national organisations will need more resources than DFAT plans to provide. And it is not about just giving more money to the national organisations – some are arguably not ready for this – it is about funding the support these organisations need in order to survive and, ultimately, thrive. This support does not need to be provided by the Australian community-based organisations (CBOs) – although a case can be made for this to occur – but it does need to be provided by someone.

It is not just about money. It is about the capacity of the organisations to function effectively. NAPWHA's work with Igat Hope shows that the organisations can function effectively in-country, but need resourcing and support to do this.

### So what is needed?

The national organisations need to work together. There is significant crossover amongst constituencies and multiple shared goals. Together they need to engage with DFAT, but the conversation needs to be a new one. It needs to be about:

- The importance of safe spaces for marginalised communities, and the critical health education that can occur only in these spaces.
- An acknowledgement that constituencies are significantly shared, and that the three organisations want services to be shaped around what individuals may need at different times rather than the notion of strict institutional integrity. A person may seek services from Igat Hope at some point and, at another, from Friends Frangipani. A person might be connected to Kapul Champions while living in

Port Moresby and then to Friends Frangipani once they move to the Highlands.

- Something new. No one is asking for the continuation of the status quo. The national organisations want to create something new that builds on the learnings from the past and prepares marginalised communities for the challenges ahead.

As a priority, work must be done to initiate these conversations in Port Moresby, where decisions about funding the national organisations will be made. But these conversations might also be usefully conducted in Canberra. DFAT has a range of commitments and policy positions seen as conducive to ongoing support of the national organisations, and we should encourage DFAT Canberra to make sure all posts are applying these approaches.

**Tim Leach is a development practitioner who works a lot in PNG. He has worked for many years with Igat Hope, PNG's national organisation for people living with HIV, under a technical support program conducted by NAPWHA. He has also been a part of the AFAO team providing support to Kapul Champions, the national organisation for men with diverse sexualities and transgender people in PNG. Dr John Rule is a Conjoint Associate Lecturer, School of Public Health and Community Medicine, Faculty of Medicine, UNSW and the Principal Investigator on the National AIDS Council approved study: HIV-related Stigma and Discrimination and Human Rights in PNG (ref: RES10-014).**

### Reference

- 1 Leach, T., Rule, J. (Dr). (2013). *The Practice of Partnerships – Reflections on a decade of partnership between the National Association of People With HIV Australia and Igat Hope, the national association for people living with HIV in PNG.* National Association of People Living with HIV Australia (NAPWHA), Sydney.

# The Pacific Sexual Diversity Network: Strengthening enabling environments in the Pacific through capacity building and regional partnerships

By **Ken Moala**<sup>1</sup>

## The Pacific Sexual Diversity Network: an overview

The Pacific Sexual Diversity Network (PSDN) is a network that has been representing the interests of men who have sex with men (MSM) and transgender people (TG) in the Pacific region since 2007. The PSDN is a region-wide network of MSM and TG community organisations and projects and was formed in recognition of the need to develop a more effective regional response to the actual and potential threat that HIV and AIDS poses to MSM and TG across the Pacific.

Currently the PSDN includes representation from Samoa, Papua New Guinea, Fiji, Tonga, Vanuatu and the Cook Islands with growing ties with Kiribati and the North Pacific (Guam and the Federated States of Micronesia). PSDN has ongoing partnerships with HIVOS, New Zealand AIDS Foundation (NZAF), ACON, Australian Federation of AIDS Organisations (AFAO), and memberships with the International Gay & Lesbian Association (ILGA), Asia Pacific Transgender Network (APTNet) and Asia Pacific Coalition on Male Sexual Health (APCOM).

PSDN has a strategic plan for 2014–2019 to which future programs will be aligned. PSDN is incorporated in Samoa and its Secretariat is based in the Kingdom of Tonga. It is governed by a Board with representation from the various country networks, listed below,

which are also PSDN primary program participants.

## Tonga Leitis' Association (TLA): Tonga (158 members)

Tonga Leitis' Association (TLA) is an organisation that advocates to reduce discrimination and prevent HIV and STI for *leitis*<sup>2</sup> and vulnerable groups in Tonga. TLA holds annual awareness programs to raise awareness for condom use and human rights issues for the Tongan community and *leitis* and other minority groups. The TLA has established a focal point office and drop-in centre where they hold meetings, workshops and training on issues including human rights, health, and stigma and discrimination.

## Samoa Faafafine Association (SFA): Samoa (200 members)

The Samoa Faafafine Association works for the equality of *fa'afafine*<sup>3</sup> and other sexual minority groups. The organisation has two key objectives: to promote the universal respect for and observance of human rights and fundamental freedoms, including the elimination of all forms of discrimination; and to advocate for legal and social recognition of *fa'afafine* and other sexual minority groups in order to properly fit in with society.

SFA works closely with government ministries, such as the Ministry for Women, the Ministry of Health and the Ministry of Justice, and with Samoan non-government organisations

(NGOs). The SFA has been the lead advocate for HIV and STI issues in Samoa with assistance from key stakeholders such as PSDN, Samoa Red Cross, Ministry of Health and Ministry for Women.

## Rainbow Pride Foundation (RPF) (formerly MENFiji): Fiji

Rainbow Pride Foundation (RPF) is a not-for-profit community-based network that was formerly known as the Males Empowerment Network Fiji (MENFiji). The change in name took place in 2012, prompted by the expansion of its networks, membership, and mandate to holistically address the development needs of Fijian people with diverse sexual orientation, gender identities and gender expressions. This includes but is not limited to lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ) communities. The current focus of RPF work is on advocating for the sexual health and rights of the Fijian people with diverse sexual orientation, gender identities and gender expression, building on the work that was done by MENFiji since 2009 in the area of HIV prevention, treatment, care and support.

## Fiji Network Plus (FJN+): Fiji

Fiji Network Plus (FJN+) works with over 60 communities around Fiji, reaching over 80,000 people with information about HIV, decreasing stigma and discrimination, promoting Voluntary Confidential Counselling and Testing, and encouraging



**Above:** PSDN representatives join together for a training workshop in Auckland, New Zealand.

support for people living with HIV. FJN+ engages in advocacy activities, including taking a prominent role in all HIV-related events in the country.

FJN+ also provides care and support for people living with HIV through a number of mechanisms: peer support, liaising with health services for improved continuum of care, finding accommodation for people living with HIV who are homeless because of their HIV status, mediation, support from church leaders, reconciliation of HIV-positive people with their families and communities, and assisting members to access financial and housing social welfare support.

#### **Te Tiare Association (TTA): Cook Islands (40 members)**

Founded in 2008, Te Tiare Association (TTA) focuses on LGBTIQ issues in the Cook Islands. TTA partners with the Cook Islands Red Cross and

PSDN to develop local approaches for implementing HIV and STI awareness programs. In 2013, at the 11th International Congress on AIDS in Asia and the Pacific (ICAAP 11) in Bangkok, the Cook Islands Minister for Health launched the PSDN Strategic Plan as a step for the Cook Islands Government to address LGBTIQ issues.

#### **Solidarity: Vanuatu**

Solidarity supports men who have sex with men and the transgender community in Vanuatu, and partners with Wan Smol Bag Theatre – a community-based organisation which implements HIV awareness programs using dramatic arts and a network of peer educators who provide information about sexual health, distribute condoms in bars and nightclubs and encourage MSM and TG to visit the Wan Smolbag reproductive health clinic.

#### **Kapul Champions: Papua New Guinea**

Kapul Champions is the national network for men of diverse sexualities (MDS) and transgender people in PNG, and is based in the capital Port Moresby. Kapul Champions represents men of diverse sexualities and transgender people in national policy and health discussions. The organisation aims to raise the voices and concerns of MDS and TG through participation in the planning and implementation of HIV services, as well as to promote the protection of human rights for MDS and TG.

Kapul Champions was launched in 2012 by the PNG Minister of Health, Mr Michael Malabag. The organisation operates with funding from the Australian Department of Foreign Affairs and Trade (DFAT) and receives technical support from AFAO and Igat Hope (the national

HIV-positive organisation in PNG). Kapul Champions works closely with Friends Frangipani (PNG's national sex worker network), UNAIDS in PNG and PNG Development Law Association.

Kapul Champions is advocating to change laws in PNG that criminalise sex between men. Section 210 ('Unnatural Offences') applies criminal sanctions of up to 14 years imprisonment for the act of 'sexually penetrating any person against the order of nature' or who any person who 'permits a male person to sexually penetrate him or her against the order of nature'<sup>4</sup>. Section 212 ('Indecent Practices Between Males') imposes a charge of up to three years' imprisonment for acts of 'gross indecency' between males<sup>5</sup>.

**Kiribati and Tuvalu**

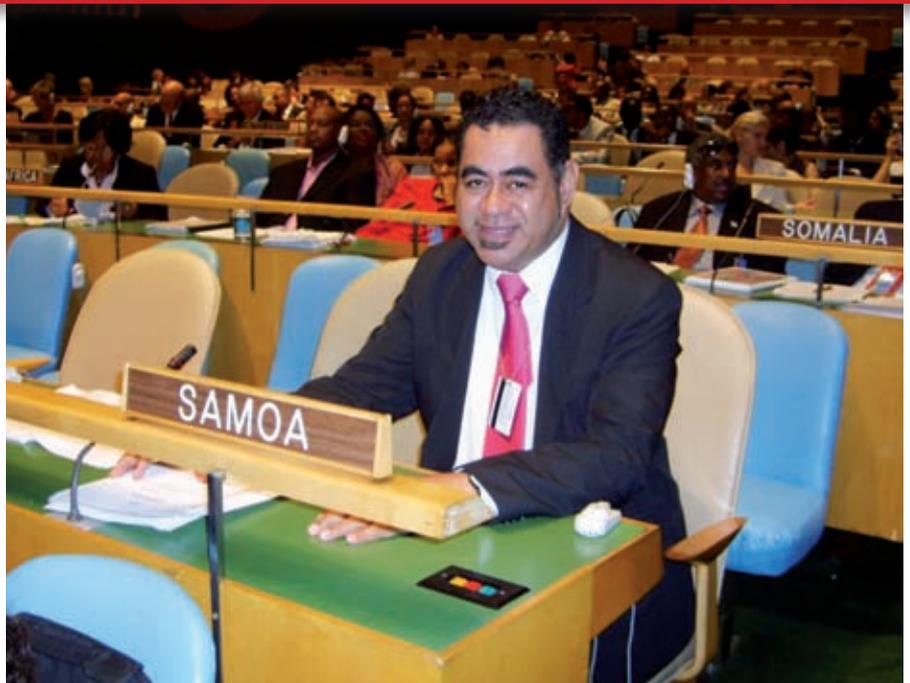
Kiribati and Tuvalu, island nations located in the Pacific Ocean, currently do not have MSM and TG networks established, however there are initial programs that will support basic training of these communities and establishment of community organisations.

**Key issues**

Despite mounting evidence of the multi-layered determinants of HIV risk among men who have sex with men and transgender people in the Pacific region, there are very few strategic interventions that specifically address the needs of these populations outside the French territories and Guam.

This lack of specific programming can be attributed to a number of factors that include:

- uncertain epidemiology and lack of data regarding MSM and TG populations and HIV rates
- laws criminalising homosexuality, which exist in nine countries in the Pacific/Oceanic region<sup>6</sup>
- little consideration or understanding of the diversity of MSM and TG sexual



**Above:** Ken Moala, representing Samoa and the Pacific Sexual Diversity Network at a global UN forum.

- orientation, gender identities, preferences and behaviours in Pacific Island contexts and sub-optimal utilisation of community knowledge and networks for prevention
- the lag between the publication of information and data and its utilisation for programming and monitoring
- persistence of considerable service access barriers for MSM and TG (including entrenched institutional discrimination in health, education and employment sectors), and little in-depth understanding of these barriers
- a predominantly ministry of health-led bio-medical approach to HIV programming at national level, leading to an undue focus on quantifying and addressing the proximate factors of HIV risk relating to HIV awareness, risk perception and sexual behaviour, rather than the underlying causes amidst unequal social structures, inadequate legal frameworks and often violent intimate relationships
- weak engagement of key populations as central actors in the response at national and regional levels, despite the

fact that they hold the keys to avert the development of HIV among these communities. This is due to inadequate capacity in administrative and technical skills of the community-based organisations currently involved in the response, the often informal nature of these organisations and networks, as well as the lack of investment in these structures beyond program funding.

**Ken Moala is Technical Advisor/ Co-Founder of the Pacific Sexual Diversity Network.**

**References**

- 1 The author acknowledges and thanks the PSDN Secretariat, PSDN chairperson, PSDN Board members and their respective organisations, Ferdinand Strobel and the UNDP Pacific Centre for their assistance and input into this article.
- 2 *Leiti* is a local cultural term which is inclusive of men who have sex with men, transgender people, gay and bisexual men and non-identifying men who have sex with men.
- 3 *Fa'afafine* is a cultural identity that encompasses and reflects the cultural context of sexual and gender diversity in the Samoan society.
- 4 See: <http://antigaylaws.wordpress.com/regional/pacificoceania/>
- 5 *ibid.*
- 6 *ibid.*

# Comparing Pacific and Australian approaches to gay men's health: reflections on the 2014 AFAO National Gay Men's HIV Health Promotion Conference

By **Isikeli Vulavou**

The AFAO National Gay Men's HIV Health Promotion Conference is held every two years. The conference is an opportunity for HIV health workers, policy makers and researchers to network, highlight best-practice, and discuss practical and strategic health promotion responses to emerging issues in the HIV epidemic in Australia. It also provides opportunities for others working in our region to network, share information and ideas, and to learn from each other.

Isikeli Vulavou, the founding Director and President of the Rainbow Pride Foundation (formerly MENFiji) and current Fijian representative to the Pacific Sexual and Diversity Network (PSDN), was one of 110 delegates who attended the 2014 conference, held 7–10 April in Sydney. In this article, Isikeli reflects on his experiences at the conference, and shares some insights about differing approaches to gay men's health in Fiji and Australia.

I first received notification about the call for scholarships for the AFAO National Gay Men's HIV Health Promotion Conference in January when the PSDN secretariat circulated a call to all its board members. It instantly grabbed my attention, as there has never been an opportunity in Fiji nor in the Pacific region (excluding Australia and New Zealand) for a conference solely focused on Gay Men's Health. After reading the background information I became keener to participate and wrote to the conference secretariat to see if the conference was open to participants from outside Australia – the Pacific in particular – and to see if scholarships were available.

The initial reply was that scholarships were open to the Pacific, but I would have to pay some costs. I approached two UN organisations based in Suva for assistance but this was declined due to unavailability of such funds. However, two days later I received good news that the conference organisers would cover registration, and that the Albion Centre could cover travel and accommodation

under the Pacific Healthcare Workers Support project in which MENFiji (now Rainbow Pride Foundation) was a collaborating partner.

I arrived in Manly, Sydney Australia on 7 April, not sure what to expect. I was both excited and anxious about all the new things I would learn during the three-day conference.

The vast difference between the HIV response in developing countries and developed nations like Australia was clearly evident during the first afternoon's information sharing session. I joined a group workshop reviewing health promotion campaigns and social media strategies currently used in Australia and New Zealand to advocate for and mobilise communities, impart knowledge and influence behaviour change. In these discussions, several health promotion staff shared examples of Australian and New Zealand health promotion programs using mobile and internet technologies to increase coverage and mobilise target populations.

The different scope of HIV programs for gay men and other men who have sex with men (MSM) in affluent countries compared to resource limited settings like Fiji was immediately obvious. Most of the target audience in Australia and New Zealand owns a smart phone and has easy access to the internet, which is not the case for similar target audiences in Fiji and the Pacific. Discussions in the workshop even covered using different mobile applications to reach different segments of the target population – at this point I was totally lost!! However, the two days that followed were very informative and gave some insights into the respective differences in HIV responses to address the epidemics in Australia and in Fiji.

Fiji is classified as a low prevalence country, with estimates from UNAIDS and World Health Organization (WHO) indicating the number of people living with HIV in 2012 to be around 1000, and a prevalence rate of HIV among 15–20 year olds at approximately 0.2%.<sup>1</sup> Although there has been no epidemiological HIV sero-surveys conducted for the general population, the number of cases identified among HIV tests undertaken annually supports these estimates. In 2012 and 2013, the total number of new HIV infections identified was 62 and 64 respectively.<sup>2</sup> Unlike the picture in Asia, where HIV transmission is largely among men who have sex with men, sex workers and people who inject drugs, the same cannot be said about the Pacific and Fiji. The main mode of transmission in Fiji is primarily heterosexual followed by perinatal,

homosexual and bisexual, and one case related to injecting drug use, noted some years back. In 2013 we saw an equal distribution of male and female cases, where previously the majority of the cases were among men.<sup>3</sup>

In Fiji, the low prevalence rate among gay men and other men who have sex with men results in the response and strategies used for these men focusing on conventional preventative strategies such as safe sex promotion, mainly through condom use. Currently, peer education is the main approach used to promote safe sex among men who have sex with men and transgender people in Fiji. Given our strong oral cultural traditions, where interpersonal communication tends to appeal more, face-to-face communication with peers is both low-cost and effective. MENFiji has also organised event-based safe sex campaigns with Information Education and Communications (IEC) materials like posters, drop down banners and t-shirts distributed to disseminate key messages on safe sex. At the 2014 International AIDS Conference I will share a poster outlining the Condomising Suva Hotspots project, where MENFiji partnered with five nightclubs to distribute condoms supplied free of charge by UNFPA (United Nations Population Fund).

At the AFAO conference, a range of additional approaches were discussed – I found myself listening and participating in discussions where the prefix sero- was frequently mentioned,

issues of gay men and men who have sex with men living with HIV were raised frequently, and the use of treatment as prevention and pre-exposure prophylaxis was covered.

Most of these terms I heard I had come across before, but never understood their meaning, nor made an effort to understand them, as they were seldom used in strategy discussions for HIV responses for men who have sex with men or transgender people back home. I learnt how numerous HIV programs targeting gay men in Australia were using rapid testing, while testing in Fiji is very low across the board – those who do get tested are often tested through opportunistic events, and then often do not return to the clinics to collect the results. The conference illustrated to me how rapid testing can increase testing uptake, and would be a useful tool to advocate for in Fiji. There seems to be ongoing discussions within the Fiji Ministry of Health on rapid testing, but a limiting factor has been funding.

At some points in the discussion I felt the conference was only focused on gay men living with HIV, but I soon realised this was due to the nature of Australia's HIV epidemic, which is concentrated among gay men.

The use of treatment as prevention was another interesting discussion given the challenges in translating knowledge and education into action and behaviour change, as evidenced in the results of the MENFiji Integrated Behavioural and Biological Survey.

The three main takeaways for me from the conference were: 1) how to effectively use social media to reach a target audience and disseminate information; 2) methods to mobilise target communities and advocate for behaviour change; and 3) opportunities to advocate with the Ministry of Health back in Fiji for introduction of rapid HIV testing and use of treatment as prevention strategies.

Thank you to AFAO and the Albion Centre for the funding support that ensured my participation in this very important conference. I hope that more opportunities will be afforded to other participants from Fiji and the Pacific in the future.

**Isikeli Vulavou is the President of Rainbow Pride Foundation (formerly MENFiji), a MSM and TG organisation in Fiji and a board member of Pacific Sexual Diversity Network (PSDN).**

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- 1 See: UNAIDS (2012). *HIV and AIDS Estimates (2012)*. Retrieved from: <http://www.unaids.org/en/regionscountries/countries/fiji/>
- 2 Ministry of Health – Fiji Islands. (2014). *Global AIDS Progress Report 2013. Fiji Islands*. Report submitted to UNAIDS 31 March. 6.
- 3 *ibid.*

# HIV AUSTRALIA

## Got something to say?

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**Above:** Also known as 'The Tree of Life', the Baobab tree is found in 32 countries across Africa as well as in Australia and is an enduring symbol of positivity and growth, thriving in conditions where little can survive.

## AIDS 2014: Under the Baobab Tree

By **Jill Sergeant and Finn O'Keefe**

The African Diaspora Networking Zone at AIDS 2014 in Melbourne has been organised by the Multicultural Health and Support Service (MHSS) in collaboration with the African Black Diaspora Global Network on HIV/AIDS (ABDGN) and the Australian Federation of AIDS Organisation's (AFAO's) African Reference Group.

Kwaku Adomaku, the Manager of the ABDGN and representative on the African Diaspora Networking Zone working group, has coordinated ABDGN's activities at the last three International AIDS conferences; in Mexico city (2008), Vienna (2010) and Washington (2012). Kwaku spoke to *HIV Australia* about his hopes for this important space at AIDS 2014.

'This networking zone is going to be a hub of activity and knowledge-sharing focused on African and Black diaspora (ABD) populations locally and around the globe,' Kwaku Adomako explains. 'The local energy and excitement of the Global Village will also result in spontaneous and unplanned experiences and connections that will inspire and recharge our commitment to ensuring the disproportionate impact of HIV/AIDS on ABD populations is recognised as a global issue that requires immediate action.'

The networking zone will include speakers from the Caribbean, USA, Canada, European Union, New Zealand, and Australia, discussing a wide range of issues including treatment advocacy, community HIV testing initiatives, and youth prevention initiatives.

Kwaku says that the zone will provide a much-needed space for the global ABD community to come together to highlight issues relevant to communities and their local context, which will help bring a broad range of issues affecting

ABD populations to the fore throughout the entire conference.

'My hope is that the recognition of ABD as a key vulnerable population is a common thread throughout the sessions and activities. This recognition is critical in supporting improved health surveillance, more enabling social and legal environments for ABD, greater protection of human rights, and reduced vulnerabilities across the determinants of health.'

In addition to participating in the activities taking place in the networking zone, ABDGN is also leading the coordination of the ABD Regional Session – *Stepping Up from Vulnerability to Opportunity: HIV and AIDS in the Global Context of African and Black Migrant and Diaspora Populations*, taking place on Tuesday 22 July from 11–12.30pm. Kwaku says that this will be a key session bringing issues affecting African Black Diaspora populations

to the forefront of the global dialogues taking place at AIDS 2014.

'We are very excited to be coordinating this for a second time and we intend to ensure that this regional session, which began at AIDS 2012, becomes a permanent feature of the International AIDS Conferences,' Kwaku says.

'We are also excited to share our plans for a Diaspora Declaration<sup>1</sup>, a unifying call to action that brings together the most recent evidenced-based knowledge and resources to inform the development of a global ABD framework that provides recommendations for research, policy, advocacy and programming that is integrated, grassroots, adaptable and sustainable. Activities related to the declaration will be highlighted at the Regional Session.'

'This year's conference theme, Stepping up the Pace, for me means that we can no longer be complacent. While migration and population mobility are international issues, there is a local dimension too. In the context of HIV/AIDS our communities often remain under-served, under-resourced, and unheard. We are at a crossroads, where we can combine our individual efforts to galvanise a global movement that recognises that despite the disparities between us, we share (many) strengths. The best way to effect change now is to step up our pace, and in solidarity show the global community that we are engaged, passionate and eager to make a real difference in changing the epidemic.'

**Jill Sergeant is Project Officer at AFAO. Finn O'Keefe is Communications Officer at AFAO and an editor of *HIV Australia*.**

**Reference**

1 The Diaspora Declaration: A Global HIV/AIDS Agenda for African/Black/Caribbean Diaspora Populations is a project bringing together Canadian and international researchers, community members, advocates and programmatic specialists to develop an HIV/AIDS Diaspora Declaration (DD) for African/Black/Caribbean Diaspora and migrant populations.

**HIV and African communities and HIV in Australia**

**Between 2009 and 2011, AFAO engaged in a series of consultations with African community leaders, influential stakeholders, HIV sector agencies (both culturally and linguistically diverse and mainstream organisations) and HIV-positive African people.**

The consultations presented information about the HIV response in Australia and data on HIV diagnoses among African-born people, and invited participants to identify key issues of concern in relation to HIV and their communities. The consultations were followed in 2011 and 2012 by two national forums which aimed to further support and develop the African community response to HIV in Australia.

A new AFAO discussion paper, *HIV and sub-Saharan African Communities in Australia* (right), draws upon the consultations and forums, as well as published research and interviews with HIV service providers and key stakeholders, to set out and analyse key HIV-related issues for African communities.

While this discussion paper is not available for general distribution, AFAO has developed a set of briefing papers which summarise the main issues raised in the discussion paper. The papers address the following topics:

- An overview
- Men
- Women
- Young people
- Gay men and other men who have sex with men



- Criminalisation
- Prevention and awareness
- Stigma.

The briefing papers are available for download at [www.afao.org.au](http://www.afao.org.au), and three – An overview, Young people and Stigma – are also available in French.



**Above:** Sem Mabuwa (consultant), Elizabeth Mlambo (Kirby Institute), Jill Sergeant (AFAO) and Kudakwashe Tuwe (New Zealand AIDS Foundation) at the inaugural AFAO National Forum on HIV and African Communities, May 2011, Sydney.

# HIV and sexuality: why are people with disabilities left behind?

By **Suzanne Lau Gooley** and **Dr Paul Chappell**

The prognosis and progress for people living with HIV (PLHIV) have been extraordinary over the last two decades. Most HIV-positive people who access antiretroviral therapy (ART) now live with a manageable chronic illness, instead of facing an ugly, premature death.

The catastrophic scale of the AIDS pandemic drove enormous changes in health services, education, socio-cultural and economic development. HIV and AIDS was not only a medical crisis, but also a product of poverty, power, gender and marginalisation. HIV required new paradigms of infectious disease control – prevention through caring for HIV-positive people and those most at risk, rather than punishment through quarantine and fear-based awareness campaigns.

Effective responses to HIV have also been based on protecting the human rights of the most vulnerable and marginalised groups – gay, lesbian, bisexual, transgender, queer (GLBTQ) communities, women, young people, sex workers, people who inject drugs, migrants, and people from culturally and linguistically diverse (CALD) backgrounds; however, one group has been left behind. Why aren't people with disabilities included?

HIV and AIDS has forced us to speak openly about what used to be hidden and taboo subjects, such as sexuality, sexual health and sexual practice, and to provide HIV information and sexuality education for many target groups – what about the needs of people with disabilities?

According to the first ever *World Report on Disability*, published by the World

Health Organization in 2011, nearly one billion people, or 15% of the world's population, are living with a disability.<sup>1</sup> The prevalence of disability is also growing due to population ageing and the global increase in chronic health conditions, including HIV and AIDS. In addition to these high prevalence rates, increasing evidence also suggests that people with physical, intellectual<sup>2</sup>, cognitive, sensory or mental health disabilities are at equal, if not increased risk to all known HIV risk factors. For example, poor access to information on sexual and reproductive health on HIV/AIDS; poor access to health care, including HIV/AIDS services; poverty and marginalisation; and higher rates of sexual abuse and exploitation than their non-disabled peers.

Despite these increased risk factors, people with disabilities are rarely included in HIV and AIDS policies and programs because they are often not perceived as being at-risk of acquiring HIV. One of the underlying reasons for this is due to some widely held misconceptions about the sexualities of people with disabilities.



'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain.'

— Ann Finger, Disability Activist

Prominent socio-medical discourses in most societies construct people with physical or sensory impairments as incapable of experiencing sex, romantic love, or relationships. In addition to being described as asexual, common public perceptions view those with intellectual impairments or mental illness as indistinct, over-sexed and unable to control their sexual desires.

These misconceptions surrounding sexuality and disability have not only drawn attention away from the sexual agency of disabled people, but also from the socio-cultural meanings of disability and desirability. In addition, these misconceptions portray people with disabilities as one homogenous group, failing to recognise that they also form part of other key populations at risk of HIV exposure, such as men who have sex with men, sex workers and people who inject drugs. As a result, very few countries around the globe consider disability when collecting HIV prevalence data.<sup>3</sup>

Unfortunately, although the global disability movement has made great strides in promoting disability rights, they have been slow to recognise sexuality as a matter of human rights. As summed up by Ann Finger, a prominent disability activist:

*'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about – and formulate strategies for changing*

– discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction'.<sup>4</sup>



The perception of people with disabilities as non-sexual routinely results in the suppression of sexuality, notably affecting young people. Young people with disabilities are generally discouraged from engaging in discussions around sexuality. Furthermore, combined with poor access to education due to physical and attitudinal barriers, young people who have a disability often receive little formal sexuality education, since it is believed that they do not need such knowledge or will become promiscuous if it is provided.

Outside of school, parents of children with disabilities are also often reluctant to discuss sexuality and HIV with their children, perhaps in the belief that by not talking about sex they are protecting their children from future rejection and vulnerability to sexual abuse. Although similar behaviours occur among parents of children without disabilities, this silence surrounding sex and sexuality is felt more acutely among young people growing up with a disability, because it is commonly believed that sex will never be part of their lives.

Despite these misconceptions, there is a growing awareness of the need to include children and adults with disabilities in sexuality and HIV services. For example, in South Africa, the Health Economics and HIV and AIDS Research Division (HEARD), has developed an intervention toolkit

for educators who teach sexuality education to learners with disabilities in South Africa's Life Orientation lessons. Likewise, Disability, HIV and AIDS Trust (DHAT)<sup>5</sup>, a regional disabled people's organisation (DPO) has been established in Zimbabwe to promote the rights of people with disabilities living with or affected by HIV, AIDS, tuberculosis, cervical cancer, and including sexual and reproductive health rights.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>6</sup> was conceived because all existing UN conventions had failed to protect persons with disabilities (PWDs). The UNCRPD came into force in 2008, and so far, has been ratified by 147 countries.<sup>7</sup> But how far have people with disabilities come as a result?

Article 25 (a) of the UNCRPD states that governments: 'shall provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.'<sup>8</sup>

Article 23 states that governments: 'shall ensure that :a) The right of all

persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized; b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided.'<sup>9</sup>

People living with HIV have demanded their human rights and those of other vulnerable groups be protected and upheld, as the foundation of effective responses to the HIV pandemic. HIV is recognised as a disability under anti-discrimination law and the UNCRPD. But where is the HIV community's advocacy, support and solidarity with the disability community?

People living with HIV (PLHIV) and people with disabilities (PWD) share similar experiences of stigma, discrimination, devaluation and exclusion. Neither people living with HIV nor people living with disabilities are regarded as 'normal' sexual beings. Considered unworthy of motherhood, women with disabilities and HIV-positive women still routinely undergo forced sterilisations and abortions in many parts of the world. However, neither the PWD nor the PLHIV movement regard people living with HIV as having a disability, despite the fact that both groups experience the debilitating effects of stigma, and have increased care and support needs.

Both the HIV and disability communities demand meaningful involvement and equal partnerships, and reject charity or medical models, that devalue or disempower them as patients or weak, dependent welfare recipients. People with disabilities have called for 'Nothing about us without us' since the 1980s, and the early AIDS activists also supported the Americans with Disabilities Act.<sup>10</sup> The GIPA principle of meaningful involvement

People living with HIV (PLHIV) and people with disabilities (PWD) share similar experiences of stigma, discrimination, devaluation and exclusion. Neither people living with HIV nor people living with disabilities are regarded as 'normal' sexual beings. Considered unworthy of motherhood, women with disabilities and HIV-positive women still routinely undergo forced sterilisations and abortions in many parts of the world.

of people living with or affected by HIV was formalised by 42 countries at the Paris AIDS Summit in 1994.<sup>11</sup> Both movements desire genuine social inclusion, where they live with dignity and are valued participants and contributors in society.

Individual disability activists and people living with HIV have called unsuccessfully for coalitions between PLHIV and PWD since the mid-2000s.<sup>12</sup> Both movements have different strengths and can complement and learn from each other. People with disabilities and people with HIV both need to break down their beliefs based on stigmatising stereotypes about each other and focus together on their common goals of access, equity and genuine social inclusion.

Australia's successful HIV strategies have incorporated partnerships with key communities, but its domestic and international HIV programs in treatment services and capacity building of PLHIV organisations have not linked with people with disabilities and DPOs. The National Association of People with HIV Australia (NAPWHA) was a member of the peak Australian Federation of Disability Organisations in 2004–2013, but withdrew to focus on wellbeing instead of disability.

An urgent alliance is needed between people living with HIV, HIV and development practitioners and people with disabilities, DPOs, disability practitioners and donors. HIV is not only a risk to people with disabilities in Africa, but also to other regions, especially in Asia which is home to two-thirds of the world's population. HIV, development and gender violence programs must also encompass disabled people.

The 20th International AIDS Conference (IAC) being held in Melbourne is themed 'Stepping up the Pace', to reflect the urgent need to reverse the trajectory of the HIV epidemic. However, no IAC plenary session has ever included a person

with a disability, not even the 2014 plenary titled 'No one left behind'.<sup>13</sup> Similarly, the AIDS 2014 Melbourne Declaration: Nobody Left Behind<sup>14</sup> fails to name people with disabilities as a key affected population.

Urgent action is needed now, as HIV responses are scaled-up, to ensure that people with disabilities are included, not only as service users, but also as leaders and partners in better HIV programs. There can never be an AIDS-free generation if we continue to leave behind 15% of the world's population – people with disabilities.

**The Disability Networking Zone (DNZ) will be located in the Global Village at the 20th International AIDS Conference in Melbourne. The Global Village offers free admission to the public and the DNZ will also be running a program throughout the conference, with Auslan interpreters available for most presentations.**

**Details of the DNZ program (including some conference sessions) are available at: [www.addc.org.au/events/disability-networking-zone/99/](http://www.addc.org.au/events/disability-networking-zone/99/)**

**The DNZ's theme of Leave No One Behind aims to promote awareness of the need for HIV programs to be inclusive of people with disabilities and provide opportunities for people with disabilities to participate and network.**

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# Learn from the past, live in the present, dream for the future: Melbourne Youth Force stepping up the pace

By Alex Mindel, Karen Salter, Kristine Squire, Naveen Tenneti and Nitasha Kumar

Since the beginning of the HIV epidemic, young people in Australia have played a vital role in shaping the HIV/AIDS response. By helping to deliver crucial services and providing indispensable support, young people have made an invaluable contribution to Australia's strategies and action on HIV.

Thirty years of Australia's investment in research and advocacy have resulted in many benefits. There are now 26 drugs available to HIV patients and treatment is personalised around the individual; however, the hardship of frontier treatment days still linger as a poignant reminder. José Machado, who has been HIV-positive for 24 years, recalls, 'It was very frightening. It was something you had to deal with many hours per day because, basically, some of the treatments involved taking large doses of pills at certain times of the day, at certain intervals. Very complex treatments, but also very severe on your system.'

Across Asia and the Pacific, approximately five million people are living with HIV. Young people carry much of this burden; half of all new infections in the region are among people under 25. While HIV prevalence in Australia remains comparatively low, in 2012 Australia's rate of newly diagnosed HIV infections rose by 10% – the largest increase in 20 years.

## YouthForce planning for the future

As young people from key affected populations around the world converge on Melbourne this July, the 20th International AIDS Conference (AIDS 2014) provides a vital opportunity to highlight the current situation, both locally and regionally, and form a concrete action plan for the future.

Since the 2002 International AIDS Conference (IAC) in Barcelona, young people have come together to collectively to form YouthForce – a platform for youth voice and visibility at the IAC. The YouthForce presence at the past six International AIDS Conferences has ensured young people's voices are heard and has created increased opportunities for young people to contribute to the program and learn from the wealth of knowledge gathered.

Made up of members from 26 youth-oriented partner organisations from around the world, the 2014 Melbourne Youth Force (MYF) is a platform to unite young people and those who support a global agenda, which places young people at the centre of the global HIV response. The MYF is a global network of young people committed to shaping the next generation's response to HIV in the world.

MYF member and the founder of partner organisation LetsStopAIDS, Shamin Mohammed Jr. from Canada, has been participating in IAC events since 2006. As a 14-year-old he was given the opportunity to ask Bill Clinton a question on 'how youth can commence leadership and inspiration around the world', highlighting the opportunities that youth are offered at IACs to voice their concerns and questions to a global audience.

At AIDS 2014, the 70 strong MYF core team presence promises to be bigger and better than ever, with the team focused on leveraging the presence of global leaders and ensuring the needs of young people continue to be a key focus at AIDS 2014 and beyond.

For many young people, like 21-year-old Sanele Ntobela from Dududu in South Africa, AIDS 2014 provides the opportunity to learn more about HIV

and bring this information back to local communities. By participating in the IAC, young people are also able to share stories with other conference delegates about what life is like for young people living with HIV across the globe.

Sanele is from a province that has high rates of poverty and few job and educational opportunities. He is a volunteer Youth Engagement Officer at the local drop-in centre and a leader in his community. He coaches soccer, teaches computer workshops and provides HIV education to other young people. This year he will leave his hometown for the first time to attend the IAC, where he will present two videos he created about the experience of being HIV-positive in his community and his community's knowledge of HIV.

Since last October, MYF volunteers have been working tirelessly to develop an effective platform for young people attending the conference to network, exchange ideas, advocate for change, learn new skills and, in the process, build lasting and effective partnerships.

The MYF's Melbourne 2014 Youth Pre-Conference will be held at the Victorian State Library on 18–19 July. The two day youth pre-conference has been designed to bring together 200 of the world's young leaders in the global AIDS response to provide a forum to build on the latest global youth campaign and programs, build tangible skills and debate and learn from the experiences and successes of young people from around the world. Technical sessions will be delivered by a range of local and global leaders in the HIV sector, including sessions run by UNAIDS, UNFPA (United Nations Population Fund), Restless Development, Youth Rise, Global Youth Coalition on HIV/AIDS (GYCA) and



**Above:** The world's largest World AIDS Day sign by YEAH! (Youth Empowerment Against HIV/AIDS) for World AIDS Day 2013. Photo: Andrew Henshaw.

Advocates for Youth. Sessions will focus on the post-2015 development agenda, new funding mechanisms, adolescent access to treatment, age of consent, harm reduction and peer education models.

### Youth Action Plan

In the lead up to and during the youth pre-conference, the MYF will develop the Youth Action Plan (YAP). The decision to move away from developing a youth declaration, as has been the Youth Force tradition, was a focus to shift thinking towards the need for an action-based plan set against clear time-bound goals and clear indicators so progress can be measured. As Alischa Ross, who has been involved with Youth Forces for many years reflects:

*'We know that we cannot afford to continue to produce well crafted declarations that are too easily filed*

*away and not turned into action, especially at a time when we have such great opportunity to really drive forward a powerful and committed response to HIV that builds on all our past learnings of our failures and our successes'.*

The Melbourne Youth Force Youth Action Plan will be formally presented to UNAIDS Executive Director Michel Sidibé, at the AIDS 2014 High Level Youth Symposium. The plan will ensure that both the young leaders attending AIDS 2014 and the thousands connecting via social media are actively involved in shaping the future direction of HIV youth advocacy.

In addition to the pre-conference, the MYF will host a youth reception and a number of other youth-related events in the lead-up to and throughout the week of AIDS 2014.

In keeping with past IACs, the Global Village will once again house the Youth Pavilion, a space where young people can meet, exchange ideas, relax, participate in informal workshops and listen to informative youth-focused presentations. The Youth Pavilion is open to the public and provides an exciting opportunity for non-delegates to also get involved in AIDS 2014. The diversity of young people in the MYF provides a great opportunity for knowledge transfer and skill building across the HIV sector.

Twenty-four-year-old Alyce Vella from Melbourne has been working at the Burnet Institute for a few years, and wanted to expand her skill set.

'I joined the MYF after doing some volunteer work with YEAH! (Youth Empowerment Against HIV/AIDS) – the MYF lead Australian partner'

says Alyce. 'I really wanted to be more involved on a community level, so I thought the MYF would be a fantastic opportunity to meet other like-minded young people who work in the sector'. This seems to have worked: 'My experience so far has been amazing', she says. 'I've been able to meet new people from all over the country (and world!) and strengthen connections I already had with other organisations in Melbourne'. Beyond just building connections, Alyce says that being involved has helped build her skills too, 'I've gained new skills in writing funding proposals as well as engaging with people I wouldn't normally come across in my day-to-day research work.'

Since last October, members of the MYF have been utilising various forms of technology and digital communication to work together and across international boundaries on projects that have tangible outcomes. The opportunities the MYF provides for young people at AIDS 2014 to connect and learn from each other, and to strengthen their collective voice, will have an impact far beyond July. Throughout this process, the diversity and richness of the partner organisations has resulted in MYF members learning from each other, effectively using resources and increasing their organisational capacity.

The real beauty of the MYF is the ability for those involved to transfer their new knowledge and skills back to their own local communities and organisations – a true and powerful example of young leaders in action and the power of connecting like-minded individuals.

As Alyce says, 'AIDS 2014 is shaping up to be a very memorable event, and I can't wait to celebrate the hard work of the MYF with my new international and local friends!'

You can read more about the Melbourne Youth Force, our activities and incredible partner organisations at [www.aids2014community.org/youth](http://www.aids2014community.org/youth) We'll also be posting more information and opportunities to be involved in



**Above:** World AIDS Day 2013 in Melbourne. Photo: Andrew Henshaw.

the lead up to and during AIDS 2014 on our social media channels [www.facebook.com/youthaids2014](http://www.facebook.com/youthaids2014) and @youthaids2014.

We hope to see you there!

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**Toronto, Canada. Naveen Tenneti is the Chair of the Australian Medical Students' Association's Global Health Committee and Co-Chair of the Youth Pavilion Sub-committee for AIDS2014. Karen Salter is the Co-Chair of the Melbourne Youth Force Media and Communications Sub-committee and works at SA Health in Adelaide, South Australia. Nitasha Kumar is part of the Melbourne Youth Force Pre-Conference Sub-committee and is completing her PhD at Monash University, Melbourne, Victoria.**

# Community-based responses to HIV in developed Asia: challenges and approaches for lesbian, gay, bisexual and transgender (LGBT) people<sup>1</sup>

By **Laurindo Garcia** and **Jane Koerner**

## Introduction

Developed Asia is a sub-region within Asia, and has been referred to by the Asia-Pacific Coalition on Male Sexual Health (APCOM) in its regional strategy and response to HIV among gay men, other men who have sex with men (MSM) and transgender people since its inception in 2007. The countries/territories of developed Asia include Hong Kong, Japan, Macau, Singapore, South Korea and Taiwan – settings with similar characteristics including relative socio-economic prosperity, rapid uptake of internet and other technologies, and high rates of regional travel.

While a basic level of universal health care is provided by governments across developed Asia, free access to treatment for people living with HIV is not necessarily a given. In addition, recent prevention options such as post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP) are not available in developed Asia and there is little open debate about their implementation, indicating the difficulties in getting HIV prevention for gay men and MSM on the public health agenda in this sub-region.

Consistent with many countries in Asia, strong cultural taboos exist in relation to homosexuality and sexuality in general, and many gay men, MSM and transgender people are not openly visible in society. Although we use the terms gay and bisexual, MSM and transgender throughout this paper,

we acknowledge that for many of these people, these identities may be irrelevant to their lived experience. Despite the recognition by UNAIDS that human rights for lesbians, gay men, bisexual and transgender people (LGBT), access to LGBT friendly health services, and protection from discrimination are critical enablers in any effective HIV response<sup>2,3</sup> – it is clear that these elements are missing in developed Asia and the rights of people from sexual and gender minorities including LGBT are far from assured.

This paper will outline the epidemiology and response to HIV in developed Asia in relation to gay men, other MSM and transgender people; identify barriers to scaling-up testing and treatment; and present some examples of community-based responses. Finally, we give suggestions on what is needed for an effective response to HIV among gay men, other MSM and transgender people in developed Asia.

## Epidemiology and response

In Asia, the HIV epidemic disproportionately affects men who have sex with men. Where data exists

on transgender people, HIV prevalence is significantly higher.<sup>4,5</sup> Modeling by the Commission on AIDS in Asia predicted by 2020, 50% of new infections in Asia would be among MSM and transgender people<sup>6</sup> and this trajectory was confirmed in the UNAIDS Global report 2013 data on HIV in Asia and the Pacific<sup>7</sup>.

In most low and middle income Asian countries there is now reasonably robust epidemiology on HIV prevalence, risk behaviours and HIV prevention program coverage, with most research funded by international donors. Despite having relative wealth, developed Asia lacks nationally coordinated data on HIV prevalence and incidence, rates of HIV testing and condom use, and on the percentage of gay men and other MSM reached by prevention activities. Virtually no data is available on transgender people in these countries/territories. While HIV prevalence rates among MSM in developed Asia are low by global comparisons with prevalence ranging from 3.1% to 5.8%, the numbers of annual infections are increasing steadily.<sup>8</sup> The few behavioural studies among MSM in developed Asia point

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to low rates of condom use and HIV testing, high rates of regional travel and high numbers of sexual partners enabled by the internet, as well as drug-use during sex as implicated in HIV transmission.<sup>9–13</sup>

Low levels of advocacy to address HIV among gay men, other MSM and transgender people are reflected in the fact that few countries/territories in developed Asia have national AIDS plans, and HIV activities focus on general heterosexual transmission even though HIV transmission rates in heterosexual populations are comparably low. The poor visibility of these groups is evident in a lack of risk assessments in national epidemics, and low levels of funding and political will to affect a community-level response. Community-based organisations exist but their scope and number are nowhere near sufficient to reach the recommended 80% of MSM to affect a reduction in HIV infections (including condom use during anal sex, and regular HIV and STI testing).<sup>14</sup>

The situation faced by MSM in Taiwan, Bangkok and Manila in the 2000s shows how rapidly HIV infections among MSM can increase in the face of poor epidemiological surveillance, inadequate funding of community responses, and inadequate government leadership, investment and action. In Thailand, HIV prevalence increased from 17.3% in 2003 to

30.8% in 2007. This was mirrored in Taiwan, when between 2005 and 2010 HIV prevalence among gay men and other MSM increased from 17% to 71%.<sup>15,16,17</sup> In the Philippines, HIV diagnosis among MSM increased by 114% and 214% respectively between 2003 and 2008.<sup>18</sup> These rapid increases show the importance of adequate monitoring of HIV prevalence, incidence and sexual behaviours as well as the necessity to increase community-based programs targeting MSM and transgender people.

### Barriers to scaling-up testing and treatment

Increasing infection rates indicate an inadequate response to date, and government policies as well as prevailing cultural and social norms have been barriers to scaling-up HIV testing and treatment. These include:

- **Criminalisation of people living with and most-affected by HIV**, which discourages people from key affected populations from engaging with government health services. Policies requiring reform include: 377A of the Singaporean Penal Code, which criminalises sex between men; criminalisation of HIV transmission in Singapore and Taiwan; criminalisation of non-disclosure of HIV status to sexual partners deemed high-risk in Singapore; and criminalisation

and forced rehabilitation of people who use drugs, including non-injecting drug users, in all countries/territories.

- **Institutionalised discrimination against people living with and most-affected by HIV** – for example: travel restrictions on foreigners living with HIV to enter Singapore; forced deportation of migrants living with HIV in Singapore and Taiwan; cases of denial of employment and/or insurance for people living with or affected by HIV in Singapore, South Korea and Taiwan; and restrictions that prevent positive portrayals of same-sex attracted people in Singaporean media, this entrenching intolerance and stigmatisation against these groups.
- **Inadequate investment, capacity-building and leadership for advocacy and support services for people living with HIV and people most-affected by HIV**, which has inhibited meaningful participation in policy debates about access to treatment, government subsidies for testing and sexual health services, and the quality of health services.
- **Cultural taboos and stigma**, which make public discourse about sex, drug use, safer sex, risk reduction, harm reduction and positive portrayals of sexual minorities problematic and difficult to scale-up.
- **Poor visibility and advocacy of transgender communities in all countries in developed Asia**, which is facilitated by a poor understanding of the complexities of transgender and intersex identities which render many people invisible.
- **The conflation of gay and bisexual men and transgender populations despite their distinct health issues**. There is a need to increase accessibility to gay, MSM and transgender-friendly HIV, STI and sexual health services.

The situation faced by MSM in Taiwan, Bangkok and Manila in the 2000s shows how rapidly HIV infections among MSM can increase in the face of poor epidemiological surveillance, inadequate funding of community responses, and inadequate government leadership, investment and action. In Thailand, HIV prevalence increased from 17.3% in 2003 to 30.8% in 2007.

### ■ Lack of a multisectoral

**response.** In East and South East Asian countries, international development assistance builds capacity for community-based service-providers. Strengthening community systems is acknowledged as an essential activity by the Global Fund to Fight AIDS, TB and Malaria and the US Government's PEPFAR program. Strong community systems are also acknowledged as critical enablers in achieving Millennium Development Goals (MDGs) by UNAIDS in its investment framework guidance to domestic governments.

### Community level approaches

Despite the barriers identified above, there are groups mobilising to increase the visibility of LGBT issues and affect a response to HIV in developed Asia.

For sexual minorities stigmatised within Asian societies, the internet plays a valuable role in helping LGBT people to meet and access HIV and sexual health information, while also serving as a source of LGBT news. There are a number of LGBT portal sites in developed Asia; examples include Fridae ([www.fridae.asia](http://www.fridae.asia)), Utopia Asia ([www.utopia-asia.com](http://www.utopia-asia.com)), and Gay Star News ([www.gaystarnews.com](http://www.gaystarnews.com)). While the internet has been identified as a possible facilitator of risk, in that higher frequency of meeting sexual contacts by internet may be related to higher rates of unprotected anal sex, it also has significant potential to provide information on HIV prevention and treatment, and facilitate organisation of networks for care and support.

Due to the lack of government support, community-based groups in developed Asia have had to be creative in instigating support and sponsorship from private and corporate donors. Often the sources of these have been companies and individuals from LGBT communities. While private sector engagement provides a significant

entry-point for LGBT community groups to work in partnership to raise the issues they face, private sector engagement is not without its challenges. These include difficulties in engaging business leaders, and the lack of discourse on HIV care and support for people living with HIV and reduction of HIV-related stigma and discrimination within current 'diversity and inclusion' activities. This private sector support is commendable, but it cannot be relied on to fund national-scale prevention programs and treatment and support for gay men, other MSM and transgender people. Significant resources, planning and coordination is needed in order to have a significant and lasting impact on HIV incidence in key populations.

### Where to from here?

While the community responses to HIV in developed Asia are nascent, there is growing interest and potential to increase organisation on LGBT health and human rights. Initiatives such as DAN (Developed Asia Network on Sexual Diversity and HIV) and others that actively transfer good practice (see breakout box overleaf) are a valuable source of innovation and support for groups concerned with LGBT health and should be replicated across developed Asia.

The pressing need is to increase funding and political commitment to

community-based HIV prevention, care, treatment and support. Links need to be strengthened between organisations, local health providers and other government agencies to facilitate dialogue on the problems and challenges faced by LGBT people in order to increase inclusiveness of existing programs and reduce stigma. Increased efforts are needed to share data and monitor prevalence and incidence among gay men, other MSM and transgender people.

In order to reduce HIV infections among gay men and other MSM and a relatively unknown epidemic among transgender people, increased community-based capacity is needed to: increase access to and promote the use of condoms with lubricant; provide LGBT-friendly harm reduction services for people who use alcohol and drugs; offer reliable HIV testing and treatment; and offer general mental health support for an often marginalised community. Invisible populations such as non-gay identified MSM and transgender people are in urgent need of tailored interventions. Furthermore, new prevention methods including rapid HIV testing, PEP and PrEP need to be investigated for implementation within developed Asia.

The steady increase in annual HIV infections among gay and bisexual men underscores the urgent need for action. The failure of most developed

In order to reduce HIV infections among gay men and other MSM and a relatively unknown epidemic among transgender people, increased community-based capacity is needed to: increase access to and promote the use of condoms with lubricant; provide LGBT-friendly harm reduction services for people who use alcohol and drugs; offer reliable HIV testing and treatment; and offer general mental health support for an often marginalised community.

## Community-based responses to HIV in Asia

Examples of community-based responses that are working to effect a health and human rights response for gay men, other MSM and transgender people in developed Asia include:

### Information sharing and networking

#### ■ DAN (Developed Asia Network on Sexual Diversity and HIV)

In 2010, a community-led network was formed among civil society organisations from five countries/territories as a result of the 1st Developed Asia Regional Consultation on HIV in MSM and Transgender People, held in Singapore in December 2010. The Developed Asia Network on Sexual Diversity and HIV, which was formed from this meeting and has focused on building the capacity of community actors in each of the countries to advance advocacy and social justice on issues related to HIV and sexual and gender minorities. In 2014, the DAN secretariat hopes to embark on a regional capacity-building program to improve the skills of member community advocates to develop long-range advocacy strategies, mobilise resources and engage stakeholders more effectively.

### Improving the visibility of transgender communities

#### ■ Asia Pacific Transgender Network

The Asia Pacific Transgender Network (APTN) provides a platform to enable transgender women and men in the Asia and Pacific region to organise and advocate for the improvement to their health, protection of legal, social and human rights, and enhancement of their social wellbeing and quality of life. APTN recognises HIV issues affecting transgender people, and advocates for improved access to appropriate prevention, treatment and care services as for HIV and other sexually transmissible infections. The Network has published several key policy and technical reports, and has developed recommendations on the protection and promotion of transgender rights that can be used by governments and partner organisations in national and other action plans.

#### ■ Transgender Resource Center, Hong Kong

Hong Kong's Transgender Resource Center (TRC) is one of the few community-based organisations in developed Asia that provides support, educational material and advocacy specific to issues facing transgender people. The work of TRC is indicative of increasing momentum across Asia for community-level advocacy on transgender issues. Much of this movement has been catalysed by the regional HIV response.

### Addressing HIV stigma and raising visibility of people living with HIV

#### ■ Living Together

Living Together started as a project to raise the visibility of people living with HIV within the gay community and wider population in Japan, but has since been adapted to other settings including Mongolia. A number of HIV community groups and support groups for people with HIV collaborated to produce 'Living Together' stories by people living with and affected by HIV. The stories are about being diagnosed, the everyday experience of living with HIV, having a friend or partner with HIV, getting tested, and experiences of risky and safer sex. The Living Together materials have been used in various events including photo exhibitions, radio programs, and music events with public readings accompanied by DJ or live music. The stories and readers' impressions enable the Living Together message to be personalised creating a powerful tool in combating HIV-related stigma.

#### ■ Taiwan Lourdes Association and the Positive Alliance, Taiwan

Taiwan Lourdes Association aims to improve the quality of life for people with HIV through care and support programs. It works with the Positive Alliance of Taiwan who engages with decision-makers to improve access to HIV treatment. The need for direct community advocacy has become more urgent in recent years as the Taiwanese government has considered rolling back the government subsidy of HIV treatment<sup>17</sup> despite global calls to increase HIV treatment access. These cuts would potentially undermine the recent progress made in Taiwan's HIV response.

#### ■ PLUS: B-Change Foundation

PLUS is a web-app which uses social networking to enhance connections between gay men and other MSM living with HIV so that they can help each other and understand they are not alone, and to find local services to support their health. The platform has been built for HIV-positive MSM in Bangkok, Kuala Lumpur, Jakarta, Manila and Singapore using the languages native to these cities. All registered members have full control over their privacy settings in order to create and maintain a safer space for users. PLUS will be released in a public beta-version in June 2014.

### Addressing diversity and inclusion of LGBT people in the community

#### ■ Pink Dot

Pink Dot started in Singapore in 2009 but has been adopted in other places such as Hong Kong and Japan and has been an enormously successful campaign that raises the visibility of LGBT people. Pink Dot has become synonymous with tactical social media-based advocacy (including YouTube videos) that mobilises followers towards a day of action where people are rallied together dressed in pink to show their support for the LGBT community. The last Pink Dot in Singapore attracted over 21,000 people.

#### ■ Out On The Street

Community Business, a Hong Kong-based NGO, provides technical assistance for multinational corporations interested in diversity and inclusion in the workplace, including resources for business leaders and human resource managers. The engagement work conducted by community stakeholders, LGBT employee groups (in particular Asia's Interbank Forum) and collaboration with Community Business resulted in an executive commitment to diverse and inclusive workplaces at the Out On The Street Asia event in 2013. A follow-up event is scheduled for late 2014.

Asian governments to sufficiently allocate HIV expenditure toward evidence-based interventions alongside policies that enable communities is, ironically, contributing to an expansion of concentrated HIV epidemics among their citizens who are gay, MSM or transgender. Considering that the cost of antiretroviral HIV therapy in this region are among the world's highest – due to a lack of access to generic medicines – the cost of HIV treatment significantly outweighs the cost of prevention. These costs are largely avoidable – but the failure to invest in strengthening and sustaining a community-based response leaves developed Asia lagging behind its low and middle income neighbours.

A paradigm shift towards more regular HIV testing, earlier initiation of treatment, the use of new prevention technologies and increased funding for community-based approaches that serve key populations has gained traction in the emerging economies of the world. It is high time that developed Asia matches its economic success with comparable public health outcomes for all its citizens.

## Acknowledgements

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- We use the terms 'lesbian, gay, bisexual, transgender' (LGBT) to describe what is actually a much wider range of identities and sexualities, and also acknowledge that such terms may not be relevant to the lived experience of many people in developed Asia. Many LGBT groups in developed Asia are conscious of the labelling problems associated with the use of foreign and local terms and some use language and imagery to show inclusiveness which would be difficult to adequately describe in the scope of this paper.
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# Enhancing partnerships across the region: Australia Awards Fellowships

By **James Malar**

## Introduction

The Australian Federation of AIDS Organisations (AFAO) International Program is working to enhance partnerships across Asia and the Pacific. One way that this work is continuing is through a project that is engaging directly with HIV/AIDS and men who have sex with men (MSM) and transgender (TG) organisations across the region as part of the Australia Awards Fellowships (AAF) program.

AFAO is partnering with the Asia Pacific Council of AIDS Service Organisations (APCASO) and the Asia Pacific Coalition On Male Sexual Health (APCOM) to bring together participants from HIV/AIDS and MSM and TG organisations in Cambodia, Myanmar, Vietnam, Laos PDR, Indonesia, Timor Leste, Philippines, Cook Islands, Fiji, Samoa, Tonga and Vanuatu.

The program will see a total of 50 advocates and leaders from community organisations, representing 13 countries, each participating in one of two month-long training programs being held in Australia. The training has been timed to coincide with the 2014 International AIDS Conference (IAC) and will continue after the conference in the form of a twelve-month mentoring and leadership program, facilitated by the Australasian Society for HIV Medicine (ASHM).

## What are the Australia Awards Fellowships?

Administered by the Australian Government Department of Foreign Affairs and Trade (DFAT), the AAF program aims to develop leadership, address priority regional development issues, and build partnerships and

links between Australian organisations and partner organisations in Asia and the Pacific. The program's goal is to develop the skills and knowledge of current and aspiring leaders in priority areas to provide support in advancing key regional policy objectives and increase institutional capacity of partner countries. AAF projects are designed to complement individual bilateral country programs by offering flexible learning opportunities that address current and emerging needs at the country, sub-regional and regional levels.

## The AFAO AAF programs

The AFAO AAF initiative is split into two groups, involving 25 participants each. One program focuses on strengthening HIV/AIDS civil society policy and advocacy capacity in Asia and the Pacific, while the other aims to strengthen MSM and TG policy and advocacy capacity among regional and sub-regional networks in Asia and the Pacific.

These two programs, running in tandem, will provide representatives from Asia and the Pacific with opportunities to build skills and capacity in advocacy, leadership, legal frameworks, social research and policy development; and also give participants the unique opportunity to experience and participate in an international HIV conference (an opportunity that will no doubt ensure the voice of Asia and the Pacific will be strongly represented at AIDS 2014). It is envisaged that the two programs will empower and equip HIV/AIDS and MSM and TG networks across Asia and the Pacific to continue to expand their influence and effectiveness over the coming years.

AFAO will be working in conjunction with ASHM, who will facilitate a twelve-month mentoring and leadership program for the AAF participants on several AAF programs. The ASHM leadership and mentoring program will be particularly important in assisting this new network of community leaders to continue to develop, enhancing the HIV/AIDS and MSM and TG response for their local community and strengthening the community networks across the region.

Details about the two AFAO AAF programs are below.

## AAF Program 1: Strengthening HIV/AIDS civil society policy and advocacy capacity in Asia and the Pacific

This capacity development program aims to strengthen community-based capacity for advocacy to promote sustained investment for HIV responses, political commitments and investment in HIV responses for HIV based on relevant context and evidence. This program particularly targets APCASO and its members, as they play a lead role in facilitating community systems strengthening around policy and advocacy for HIV responses in Asia and the Pacific.

As many countries in the region move into middle income status and the sustainability of funding is questioned due to withdrawal of international donors and uncertainty over domestic governments commitments, the role of civil society to conduct advocacy around HIV financing and hold governments accountable to their political commitments and to providing programs to address key populations is crucial.

This AAF program will provide advocacy and policy skills and knowledge on HIV financing to steer APCASO and representatives from its members in Cambodia, Indonesia, Laos and Vietnam through challenging advocacy environments, to supported sustained funding for community-based HIV organisations and key populations, within the post-2015 landscape following expiration of the Millennium Development Goals. The program will enable APCASO to gather updates from the International AIDS Conference, and learning to support human rights advocacy and strengthen policy analysis capacity for engagement in national, regional and global policy discussions.

Rodelyn (RD) Marte from APCASO says that the AFAO/APCASO AAF partnership presents a unique opportunity for APCASO and its members to focus on skills development, away from the day-to-day pressures of carrying out the work:

*'In the course of implementing our work, the daily pressure to implement many things well and on time often leaves little room and energy for much needed personal and organisational reflection and learning. This is why the AAF is so valuable to APCASO fellows – it provides precious time, space and resources to dedicate just for learning.'*

### **AAF Program 2: Strengthening MSM/TG policy and advocacy capacity among regional and sub-regional networks in Asia and the Pacific**

It is well known that countries across Asia and the Pacific are experiencing escalating rates of HIV transmission among men who have sex with men and transgender people, particularly in large urban areas. The 2008 Commission on AIDS in Asia, Multi City Initiative, and the HIV Strategic Assessment each call for urgent investment in MSM and TG prevention, treatment and care programs.

The Asia Pacific Coalition on Male Sexual Health (APCOM) works to respond to this huge gap in funding, research, and human rights protection for MSM and TG and is AFAO's partner for this program. The AAF will support APCOM members to respond with increased advocacy and leadership to the MSM and TG epidemics in Asia. Strengthened strategic planning and leadership skills, will contribute to APCOM and members capacity to function as peak advocacy bodies for MSM and TG in Asia and Pacific. The AAF will also provide more focused learning on building specific skills in advocacy, human rights and social media focused on MSM and TG community issues.

The AAF will strengthen the skills of key MSM and TG advocates and networks in Asia and Pacific, to be able to engage more effectively and knowledgeably with national government, health service providers and other stakeholders. This will support the scale-up and accessibility of services for MSM and TG around HIV and health, as a priority DFAT issue. The AAF will also support increased advocacy around human rights protections for MSM and TG communities.

Midnight Poonkasetwattana from APCOM emphasises the broad benefits he sees resulting from the AAF, particularly with regard to the way APCOM will be equipped to respond to challenges: 'APCOM believes in working in partnerships to contribute to an effective response to HIV for key populations such as MSM and transgender people because an effective response is a well coordinated response. AFAO provides coordination and support to APCOM to jointly implement an AAF program aiming to strengthen civil society-led advocacy and leadership.

The AAF fits in with one of APCOM's four Strategic Results – to build a cadre of advocates by investing in emerging leaders and community advocates. This is crucial to be able to

keep our rights-based and evidenced-based programming to be responsive to the current needs of the changing socialisation of our communities in a highly digitalised and globalised world, and also the challenges that we continue to face for our communities to be an equal partner in the response.'

### **Conclusion**

International organisations, community organisations and governments have continually highlighted the importance of civil society and community engagement in achieving broader social and economic development outcomes for the HIV/AIDS response. Given that Asia and the Pacific constitutes the world's most populous region, and given significant economic and social changes in the region, AFAO commends DFAT and the Australian Government for their ongoing support of HIV/AIDS and MSM and TG community organisations across the region. AFAO, APCASO and APCOM look forward to enhanced working relationships between all our member and partners as we move forward.

**James Malar is the Engagement and Communications Advisor at AFAO International Program in Bangkok.**



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# Community engagement for improved outcomes for HIV/AIDS in Myanmar

By **Dr Paul McShane**

A program to strengthen the HIV/AIDS response in Myanmar was recently undertaken by Monash University under the Australian Government's Australia Awards Fellowships (AAF) program. Twenty senior health professionals from Myanmar's Ministry of Health, Universities and non-government organisations (NGOs) such as the United Nations (UN) World Food Program and Marie Stopes International, worked with Monash academics to explore community engagement strategies for addressing HIV/AIDS and maternal health in Myanmar. Monash brought interdisciplinary insights including contemporary biomedical approaches to community health care and the participants from Myanmar brought knowledge and experience of the social and cultural context in which the HIV/AIDS epidemic is being tackled in their country. There are clear mutual benefits in such programs.

Total expenditure on health in Myanmar remains low at about 2% of GDP, compared to Australia's 9.5% of GDP.<sup>1</sup> Out-of-pocket expenditure on health ranks among the highest in the world and accounted for 92% of all health expenditure in 2010.<sup>2</sup> Thus, typically, it is the poor who lack effective access to health care.

Rates of HIV infection in Myanmar are among the highest in South East Asia. Myanmar's epidemic is concentrated in select risk groups, including sex workers and their clients, men who have sex with men, people who inject drugs and the sexual partners of these groups.<sup>3,4</sup> In dealing with the HIV epidemic, Myanmar has developed a National Strategic Plan on HIV and AIDS. Although comprehensive and well-

targeted, there remains difficulty in financing this plan<sup>5</sup>, which has already entered its second phase<sup>6</sup>. The plan is coordinated by the Ministry of Health and is overseen by a Technical and Strategy Group on AIDS comprising representatives of donors, NGOs, UN agencies and the government.<sup>7</sup> This reflects the multi-sector approach to funding and ongoing efforts of international agencies. The Monash AAF program emphasised community-level approaches and sought to complement these multi-sectoral efforts directed at health care in Myanmar through engagement with key practitioners and their representative agencies.

The Monash Fellowship program focused on primary health care through proactive community engagement rather than on clinical intervention. It addressed the first strategic priority of the National Strategic Plan: prevention of the transmission of HIV through unsafe behaviour. The program was necessarily interdisciplinary, recognising that community engagement for improved health outcomes requires understanding of the cultural, ethnic, religious, social and legal context in which behaviour affecting the health of individuals is influenced. Social support networks through communities are key vehicles to transfer relevant information and knowledge to develop understanding of disease prevention strategies among vulnerable groups and the community at large.<sup>8,9,10</sup> Such issues are well understood, for example in the African contexts cited above, but cultural influences on health-related behaviour in Myanmar are not well described in the literature. Interactive inter-country programs, such as the Monash

AAF program, offer opportunities for solutions to current health problems to be developed in a culturally relevant interdisciplinary environment. Having a mix of government and NGO representatives assisted in bringing realistic and candid perspectives on cultural and social drivers of behaviour and on practical cost effective intervention strategies. An open and interactive environment with facilitated discussion sessions helped with constructive information exchange.

In Myanmar, sex work, homosexuality and use of injection drugs – all prominent modes of HIV transmission in Myanmar – are currently illegal. This not only influences behaviour, for example by discouraging individuals from seeking advice or treatment from government health agencies, but criminalises many social interactions, influences power structures and creates inequality, particularly among women. Female sex workers lack power in enforcing the use of a condom by their clients. Acting outside the law, sex workers are vulnerable to HIV infection and other sexually transmissible infections (STIs), and also to violence and other anti-social behaviour.<sup>11</sup> Male workers from Myanmar migrating temporarily to Thailand or China for employment can acquire HIV through local sex workers and then pass the virus on to their partners back home.

Continuing poverty reduction efforts will assist in reducing economic incentives for sex work and migration, and help reduce gender inequality. De-stigmatisation of gay men along with community leadership on social justice will also encourage access of vulnerable groups to necessary health services. Prominent Myanmar pro-

democracy politician and Nobel Peace Prize Laureate, Aung San Suu Kyi, is the UNAIDS Global Advocate for Zero Discrimination and therefore a powerful ally in the battle against HIV-related stigma.

With relatively few trained health professionals available, particularly in regional areas of Myanmar, there is a reliance on informal health services.<sup>12</sup> Community health workers and volunteer health workers play important roles, engaging members of the community and influencing behaviour both positively and negatively.<sup>13,14</sup> In some cases, traditional norms may be inconsistent with necessary interventions. In particular, linking evidence-based approaches to community health to the traditional care-giving provided by community health workers is vital to improving health outcomes.

Developing capacity among community health workers who understand customary norms and cultural drivers of behaviour formed a critical component of the Monash program. This strategy represents a conduit for promoting the importance of incorporating evidence-based approaches to primary health care, awareness-raising among the community harnessing trusted relationships, and adoption of practices which prevent HIV infection among community members. The Monash program enabled an exploration of evidence-based approaches to HIV

prevention and primary health care in Myanmar with the participants' knowledge and understanding of the cultural, ethnic, social and political landscape as a vital background. There is now a team of highly motivated health professionals back in Myanmar ready to further improve the response to HIV/AIDS, and strong personal and institutional relationships between Australia and Myanmar to draw on in the future.

### Acknowledgements

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# 'Using the heart': law enforcement and people who use drugs in Asia

By **Fifa Rahman, Hong Reaksmei, Pham Hoi Thanh and Olga Golichenko**

'These addicts, actually they are patients!'<sup>1</sup>

In countless countries around the world law enforcement officials continue to be at the forefront of the failing war on drugs and can be a major obstacle when it comes to implementing evidence-based HIV prevention and treatment interventions. It's not all doom and gloom, however, and thanks to the energy of progressive champions within the police and cooperation with civil society, the police are changing from the inside in some places.

## Learning from the Australian experience

Australia, particularly law enforcement in the state of Victoria, is at the forefront of such changes and is stimulating similar developments in other countries, most notably in parts of Asia. It's one of the few countries in the world where civil penalty schemes allow the police to issue fines for minor drug offences<sup>2</sup>; the police can exercise the discretion to be able to divert people who use drugs towards the health system (before or after arrest); and individuals in police custody are allowed access to HIV medicines, methadone and medical services.<sup>3</sup> Police officers in Victoria have a good understanding of public health and harm reduction.<sup>4</sup> For example, they do not park patrol cars in front of or in close proximity to a needle and syringe exchange site because this might scare people off from accessing the services.<sup>5</sup>

By comparison, our research in Malaysia<sup>6</sup> shows that the police lack information about the links between harm reduction and public health. For example, law enforcement members

in Kuala Lumpur do not know that needle and syringe exchange programs reduce the risk not only of HIV infection but also of hepatitis C. The police authorities there tend to challenge the scientific evidence relating to the efficacy of methadone. Police organisations in Victoria care about the levels of public confidence in their work<sup>7</sup> as well as being concerned with the public health needs of people who use drugs. Deprivation of medication in detention is considered a disciplinary offence in Victoria.

Police officials together with community advocates from Cambodia (KHANA<sup>8</sup>), Malaysia (Malaysian AIDS Council [MAC]) and Vietnam (Supporting Community Development Initiatives [SCDI]) visited Victoria and New South Wales in Australia last summer to find out more about law enforcement practices with a view to increasing political support of a harm reduction approach among police officials in each country. The study visits were organised as part of the Asia Action on Harm Reduction program<sup>9</sup> which is coordinated by the International HIV/AIDS Alliance with support from the European Union, and in partnership with the Australian Police Leadership program run by the Law Enforcement and HIV Network (LEAHN) with support from the Australian government.

Working with the Melbourne and Bishkek-based LEAHN global network of police and health professionals provided participants with considerable food for thought, not least because the network practises

a 'police talking to police about HIV prevention' approach, working in countries through experienced police focal points. LEAHN also champions the *Statement of Support by Law Enforcement Agents for Harm Reduction and Related Policies for HIV Prevention*, which has been signed by more than 5,000 police officers worldwide and an increasing number of police agencies.

Following the study visits, country cooperation platforms among police and civil society are in the process of being established in Malaysia and Cambodia. In this article we describe our main learnings from the study visit to Victoria and next steps.

## Malaysia: police support for health services in detention

In Malaysia, healthcare services are not available for people who use drugs in pre-trial detention. According to Ng Soon Wah, Assistant Superintendent in the Royal Malaysian Police's Narcotic Crimes Investigation Department, who took part in the study visit:

*'The most interesting point was the health management services provided by Victoria Police at the police remand centre. Victoria Police have their own doctors, pharmacists and nurses to check and take care of detainees under police custody, including patients living with HIV. This practice should be implemented in Malaysia.'*

The study visit report<sup>10</sup> and the fostering of close relations with the police officials who participated have helped MAC to get police buy-in for the introduction of medical services for those detained in holding cells. With support from key champions in the police, a committee has been

established under the auspices of the Ministry of Home Affairs to discuss a pilot project to introduce healthcare services in detention settings, starting with the police custody system at Jinjang integrated lockup centre. Drawing on the experiences of multiple stakeholders' forums in Australia, MAC now convenes the Kuala Lumpur Health and Drugs Forum which brings together different stakeholders, including the Royal Malaysian Police, to look at HIV and drug issues. A commitment has also been received from the Royal Malaysian Police to introduce the concept of harm reduction to the training curriculum for police cadets.

### **Cambodia: a 'softer' implementation of the Village/Commune Safety Policy**

The Village/Commune Safety Policy was launched by Cambodia's Ministry of Interior in 2010 and due to a priority focus on 'cleaning the streets', has driven people who inject drugs underground. This has created significant difficulties for HIV prevention programs but unfortunately the popularity of the policy among the public and politicians leaves little opportunity to advocate for changes. However, local police forces are able to apply a certain level of discretion to implement the policy in a 'softer' way, for example by referring people who inject drugs to harm reduction programs instead of arresting them.

Since last year, KHANA, jointly with the Ministry of Interior's AIDS Secretariat, has been implementing the Police–Community Partnership Initiative (PCPI), which builds police awareness of harm reduction through training. It also develops police platforms on harm reduction at a district and community level in Phnom Penh together with local community participation. To encourage international best practice and create stronger linkages between the Ministry of Interior and other stakeholders, KHANA has seconded

its communication officer to the AIDS Secretariat to help inform the PCPI training. Some 200 police officers have already participated, together with 150 commune council members, drug users' representatives and other local stakeholders.

Dr Hy Someth is program manager with the AIDS Secretariat and took part in the study visit to Australia. 'After the harm reduction training, the police will use not only their heads and hands but also their hearts to support people who use drugs,' he said. As well as applying his experiences from Australia to the PCPI training, Dr Someth is also supportive of KHANA's advocacy efforts to extend methadone maintenance therapy (MMT) services to prisons and to offer MMT takeaway doses to current patients. 'Once a drug user is sent to prison, the police are no longer responsible but we acknowledge that MMT substitutes heroin and normalises drug users' behaviour towards stopping using illegal drugs,' Dr Someth said.

### **Vietnam: gaining police support for harm reduction**

Last October the People's Police Academy, jointly with LEAHN and SCDI, organised a meeting about harm reduction between officials from Vietnam's Ministry of Public Security and civil society representatives. It was the first time such a dialogue had occurred. The ongoing collaboration between the People's Police Academy and SCDI includes research about the effects of relapse on drug use and the associated risk of criminal activity. SCDI is also working closely with the police to gain their support for

the development of harm reduction and community-based rehabilitation services in Bac Giang province.

### **Where to from here**

In many countries in Asia, such as Indonesia, Malaysia, China and India, there are some progressive policies in place that allow the implementation of harm reduction services and diversion from arrests to treatment. However they are not being implemented properly because of law enforcement policies such as police arrest quotas, which lead to the arrest and harassment of outreach workers and people who use drugs. In such cases police leadership and collaboration is required to ensure an effective implementation of drug and harm reduction policies.

In Indonesia for example, the diversion policy outlined in *Narcotics Law #35*, which seeks to divert people suspected of drug use and possession for personal use to treatment and harm reduction services instead of the criminal justice process and potentially prison, can only work if police officials (as well as prosecutors and judges) are aware of the policy – and willing to implement it.

This year the Asia Action on Harm Reduction program will support police officials and community advocates from Indonesia to learn from the Australian model. The study tour will include a visit to Harm Reduction Victoria, a peer-based organisation of people who use drugs. Participants hope to learn about various strategies to engage with people who use drugs and the support services they provide to their members. There will be discussions about how to work with police and

'The police have the authority to divert people who use drugs in Indonesia from prison towards treatment but this is not happening because of a number of structural barriers. I hope to learn from the police in Australia to help us to improve the implementation of *Narcotics Law #35*.'

— Policy Manager, Ardhany Suryadarma

government to develop policies that recognised the importance of civil society collaborating with the criminal justice system. Policy manager Ardhany Suryadarma already knows the change he wants to see: 'The police have the authority to divert people who use drugs in Indonesia from prison towards treatment but this is not happening because of a number of structural barriers. I hope to learn from the police in Australia to help us to improve the implementation of Narcotics Law #35.'

In the majority of countries in Asia, policies on drug use and harm reduction need to be amended and introduced first before, or at the same time as, asking for police leadership and collaboration. Improving relationships with law enforcement officials and understanding harm reduction through their 'lens' is critical. The study visits to Victoria have helped build trust and partnership between community advocates and police officials. As well as creating harm reduction champions within law enforcement sectors, the visits are contributing to in-country changes where both police and community advocates work together. In Malaysia, for example, law enforcement members who participated in the trip are now facilitating police training and high level briefings on HIV/AIDS and harm reduction.

According to Professor Nick Crofts from LEAHN: 'Together with other stakeholders, LEAHN focal points are building police leadership in harm reduction in countries following the study visits. What we need is the political support from governments and resources from donors to institutionalise this leadership'.

It's imperative that key donors, particularly the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria, as well as governments in Asia, fund interventions that will build support of harm reduction approaches within the law enforcement sector. This will help create an enabling environment for harm reduction services at a community level.



**Above:** Malaysian police at a training session to raise awareness of harm reduction approaches. Photo: Fifa Rahman for the Malaysian AIDS Council.

**Asia Action on Harm Reduction is a European Union funded program which enables civil society advocates in China, India, Malaysia, Indonesia, Cambodia and Vietnam to advocate for harm reduction. This is done through creating evidence-based advocacy calls, and by improving knowledge and building support for harm reduction among policy makers. The contents of this article are the sole responsibility of the International HIV/AIDS Alliance and do not necessarily reflect the opinion of the European Union.**

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# Learning from each other: the Australian-Asian partnership experience

By **Ele Morrison**

This article presents some case studies of successful partnerships between the Australian Injecting and Illicit Drug Users League (AIVL) and networks of people who use drugs in Asia, reflecting on some challenges experienced by these networks, both in Australia and across the region.

## Case study one

I first met the Coordinating Committee of the Vietnamese Network of People who Use Drugs (VNPUD) in March, 2010. This group of five people had been introduced to me through a Vietnamese non-government organisation (NGO) which provides support for the group. They had only formed a few months before and already had over twenty member groups at local levels around Vietnam, despite very few of them ever having had any funding or support. I wanted to meet with them and was going to Vietnam anyway, so organised through the NGO to have a meeting with the President. A few days before I arrived I was asked to provide a workshop. It sounds crazy now, but as probably the first peer-based organisation of people who use drugs (PUD) to ever receive funding to work with other PUD organisations in developing countries, it was an opportunity we didn't want to miss.

I delivered VNPUD's first organisational development workshop on developing a mission statement, designing a constitution, basic strategic planning and some very basic ideas for communication within the network. The idea was that these things could help them start to develop the structure and governance of their organisation and start advocating for support from other organisations within Vietnam.

The workshop was like no other I had delivered during the course of my international career. At no time in the

four day period were all five people in the room, and at no time was I told who I could expect to be there. One woman missed two-and-a-half days because she was worried about her chickens, and spent most of the time she was there on the phone. Another person left a day early and others missed periods of time to attend meetings with other organisations. They were eager to start early, but forgot to tell me and after the first day, most of them were late. They weren't so eager to stay late. But when they were there, they were some of the most enthusiastic and motivated people I've worked with. They obviously liked each other, enjoyed each other's company, and really wanted me to be happy. And the President was a tiny woman who had more charisma than most of us have in our left elbow.

At the time we thought AIVL was at the end of its work in Asia. The program was supposed to end a few months later and we didn't believe there would be any more funding. A couple of months later, against the odds, we were asked to submit a proposal for another two years of funding and we decided to include supporting the development of VNPUD in our proposal. It was only then that I found out the results of our hastily developed and slightly chaotic workshop. VNPUD had taken everything we had talked about and developed a brilliant Mission Statement and Constitution that reflected their objectives perfectly.

They were using it to show other organisations what they wanted to achieve, and were already receiving other support from stakeholders in Vietnam.

Since then, we have worked with VNPUD in several different ways. We have provided workshops, support for their launch, shared resources, brought them to international and regional events, and worked with them to develop relationships with other stakeholders. Their membership has more than doubled. Their Coordinating Committee has changed. The President, the petite woman from my first meeting, is still fearlessly leading them all. They still face serious barriers to their ability to legally register the organisation, and they still don't have much core funding. They have received funding for some activities and training over the years, all of which they use to help them navigate their next steps and develop the capacity of their members. The many organisations and relevant government departments in Vietnam know who they are. They stand up and advocate for change whenever they can. They are extremely passionate about issues like compulsory drug detention centres and the human rights of people who use drugs.

## Case study two

Recently I worked with the Coordinating Committee and a few key leaders from their member groups in another workshop. This time, I was co-facilitating with someone from one of the most successful and established PUD networks in Asia, the Indonesian Drug Users Network, PKNI. The workshop focused on training the participants to provide training on blood borne viruses, particularly HIV and hepatitis C, to their peers in the network. Over three days they learnt

the basics, as well as more in-depth knowledge about HIV and hepatitis C. The Indonesian facilitator and I were surprised to find out the extent to which a person's right to health has been ignored in Vietnam.

Many of the participants in the workshop were HIV-positive, but none knew the results of their viral load or CD4 tests. They had never been told why they had been started on antiretroviral treatment (ART) when they were, and nor were they educated about the Vietnamese standards for antiretroviral medication. Some thought they were positive for hepatitis C as well, but few had voluntarily accessed a hepatitis C test, they just knew they had been given a hepatitis C test at some point. It was most likely an antibody test, which would only have told them if they'd been exposed to the virus, not whether they had developed chronic hepatitis C. And they weren't told the results of those tests either, they just made assumptions based on the way they were treated afterwards. They learnt a lot from hearing the experience of the Indonesian facilitator, and everyone agreed people have the right to know their own health status.

**Our similarities and differences: some reflections**

The workshop was also revealing in other ways. My experience in countries around Asia is that there are many things we share with our peers in other countries. We tend to quickly develop trusting relationships over cigarettes and stories about drugs.



**Above:** Out on the road in Vietnam with VNPUD project outreach workers. Photo: Ele Morrison.

We talk to each other about things we can't easily talk about with people who don't share our experiences. This workshop, attended by people from three different countries, including two lower income countries, revealed the ease with which those similar experiences can bring out and translate into useful information across cultures. The Australian experience is relevant in many ways, but there are ways where it isn't as relevant, or isn't perceived to be as relevant. In particular, Australians who inject drugs don't have a shared history of high rates of hepatitis C and HIV co-infection. In the middle was the Indonesian experience, where harm reduction and the capacity of PUD networks have come a long way in comparison to Vietnam.

PUD networks and organisations in Asia are all fighting a lot of personal,

social and political battles, similar to many of the battles we continue to face in Australia. Over the three years or so I've known them, VNPUD have stayed the same in many important ways such as their commitment and their passion. They have also significantly changed. The amount they have grown and learnt in this relatively short period of time is incredible, and they have achieved this with very little resourcing. The partnerships we have developed with these different networks reveals something to us in Australia about where we have come from, and where our peers in other countries could be heading. At the same time, our different experiences show that we all have things to learn from each other.

**Ele Morrison is International Program Manager at AIVL**

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**Read Brenton Geyer's article, 'ENUF: social action to resist HIV stigma and promote resilience', about an Australian anti-stigma and discrimination campaign produced by Living Positive Victoria.**

Pictured: Jai Wallace, an ambassador for the ENUF campaign (enuf.org.au)

## Successful funding mechanisms to foster civil society: which way forward in China?

Experiences from the CHAIN, APCASO and AFAO Community Advocacy Initiative on the Investment Framework program in China

By **Cai Lingping, Li Yue, RD Marte and Chris Connelly**

China is at a cross road in its HIV response – a transition from international funding towards a fully domestically funded response. How this transition is managed, and the models of funding that are developed to support civil society, will determine the continuity of existing civil society organisations and the overall future effectiveness of the response.

Over the past ten years, China has made significant progress in scaling-up its HIV response. The central government has moved to strengthen coordination among HIV-related ministries and issue policies to support effective implementation of the National AIDS Strategic Plan. Government funding at all levels for the response has also increased significantly, with central funding increasing from RMB 120 million (USD 19.35 M) in 2002, to RMB 2.06 billion (USD 323.5 M) in 2010, 2.2 billion (USD 354.8 million) in 2011, and an estimated RMB 2.8 billion (USD 451.6 million) in 2012.<sup>1,2,3</sup> This means that China is one of very few countries in Asia that domestically funds the majority of its HIV response. As of 2012, 88% of China's HIV funding is reported to be domestically sourced.<sup>4</sup>

Chinese civil society and community-based organisations (CBOs) play significant roles in the country's HIV response. Under external funding from the Global Fund and Gates Foundation, civil society has been able to grow in China in an unprecedented way. Numbers of community-based organisations across the country have multiplied, providing different models for community engagement in various aspects of the response.

The crucial role of Chinese civil society and CBOs is recognised by the Chinese government, with the Chinese premier Le Kiqiang in November 2012, publicly declaring the government's commitment to funding civil society and CBO involvement as a critical part of the HIV response. However from that public statement to the present, the government has been stalled in developing a viable funding mechanism to operationalise its commitment. At the same time, international funding sources are withdrawing from China, making it increasingly difficult for many civil society and community-based networks and organisations to secure funding to continue their work and sustain established networks.

Civil society was in urgent need of a platform to discuss China's HIV funding situation and the role of civil society in the HIV response. The DFAT-supported Community Advocacy Initiative on the Investment Framework (CAI-IF) program aimed to provide this platform. Implemented by a collaboration of China HIV/AIDS Information Network (CHAIN), Asia Pacific Council of AIDS Service Organisations (APCASO) and the Australian Federation of AIDS Organisations (AFAO), the program worked to enable Chinese civil society and CBOs to take stock of their country's HIV funding scenario – particularly regarding community mobilisation, identify challenges and bottlenecks, and plan strategies together to begin advocacy on funding issues.

From late 2012 to early 2014, CHAIN, with support from APCASO and AFAO, conducted a series of

workshops to develop the capacity of Chinese civil society and CBO partners to critically engage with and use the Investment Framework to advocate for more effective financing of the HIV response in the country.

Since the Chinese government has now taken over funding the HIV response from external donors, effective engagement between civil society and CBOs is crucial. The Investment Framework has galvanised civil society and CBO dialogue, advocacy and strategising around ensuring that the Chinese government effectively : 1) funds CBOs in sufficient amounts and in a transparent and accessible manner; 2) funds civil society work on critical enablers; and 3) supports synergies between health and HIV departments and broader development ministries and sectors.

A notable aspect of this phase of the program was the readiness with which civil society took on Investment Framework thinking and approaches, and adapted these to their own HIV funding situation.

Under the CAI-IF program, CHAIN also led a nationwide survey of civil society to explore and document Chinese CBO perspectives on HIV funding. The survey was a collaboration of almost 100 representative civil society and community networks from all over the country, and represents a significant achievement for civil society in China itself. Civil society organisations contributed their perspectives and experiences to provide clear recommendations for

the Chinese government, international donors, and civil society.

Advocacy under the CAI-IF program culminated in a national CBO-government-development partners workshop in May 2014, titled 'Investing in CBOs Towards a More Effective HIV Response in China: An HIV Investment Framework from Community Perspectives.' This workshop was significant for being the first CBO initiated meeting between Chinese government and Chinese CBOs at the national level on HIV issues.

Key findings and recommendations from the survey of Chinese CBO perspectives on HIV funding presented to government in the workshop included the need to:

- develop clear policies and systems, via consultation with CBOs, to ensure that government invests in CBOs, establishes systems to support CBOs involvement in the HIV response and makes CBOs involvement a standard policy
- develop clear policy guidelines and a CBO service list on key government HIV investment areas
- invest in CBOs to work on developing an enabling environment, including on anti-discrimination, gender equality, livelihoods, advocacy, legal aid and monitoring
- set up a government information disclosure system at central and local levels to ensure CBO access to information.

Recommendations to international development partners included the

need to continue funding for Chinese CBOs in areas of capacity building and in areas of critical enablers and synergies with the development sector – areas that may be difficult for Chinese government to support – as well as continued encouragement and assistance to Chinese government to practise transparency in HIV funding and support CBO institutional development.

The Community Advocacy Initiative on the Investment Framework, and the work of CHAIN, APCASO, AFAO and all the civil society partners in China is considered by many in-country partners to be ground-breaking as the start of a new way for CBOs and government to work together. This work provides a platform for civil society and CBOs to mobilise and rally around the issue of the country's HIV funding. It also facilitates a nationwide collaboration of civil society to articulate and document funding experiences and recommendations. The recommendations were put to government representatives at the first civil society/CBO-initiated meeting, where these representatives listened to community recommendations on HIV funding, and heard about positive experiences of civil society participation and leadership in China.

The program has facilitated clear articulation of civil society and CBO issues via the survey and national workshop, enabling community perspectives on HIV funding to reach relevant decision-makers. Key messages from the community can hopefully be incorporated into the development of the mechanism for

civil society to receive government funding. In partnership with UNAIDS China Country Office and the National AIDS Commission, CHAIN continues to work to feed the CBO recommendations to higher levels of government to influence decisions on future Chinese HIV funding.

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"The consultation has been a good method and platform to improve our communication with CBOs. The CBOs suggestions for fund allocation are useful, and we may also consider inviting CBOs to discuss fund allocation policy in the future."

— Representative of the local China Center for Disease Control (CDC) who attended the CAI-IF meeting.



**HIV Australia is available online with additional content.**

**For information about the CAI-IF program activities in Vietnam, see 'How do we make change happen' in HIV Australia online.**

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

# For the community, by the community: strengthening effective responses to HIV

By Inad Rendon

Men who have sex with men (MSM) and transgender (TG) people are two populations disproportionately affected by HIV across Asia and the Pacific. In recognition of the fact that urgent investment is required to strengthen the capacity of MSM and TG communities and their organisations to participate in HIV responses at the local, national and regional level, Asia Pacific Coalition on Male Sexual Health (APCOM), in partnership with the Australian Federation of AIDS Organisations (AFAO), implemented a project entitled the MSM and TG Networks Capacity Strengthening Initiative (MSM and TG Initiative).

The project recognises two key elements that are essential for fostering effective responses to HIV. The first is the meaningful involvement of communities most affected; the second is effective community-led advocacy driven by a thorough and well-articulated understanding of local HIV epidemics. There remains a lot of work to be done, particularly at the regional level, to use this evidence to build effective prevention, care and support programs for MSM and TG communities.

This article looks at some of the ways that the MSM and TG Initiative is helping to remove barriers that hinder effective engagement and advocacy among regional, sub-regional and national MSM and TG organisations by providing support and capacity development tools to empower communities to lead effective responses to local and regional HIV epidemics.

## Building capacity

Since its inception, Asia Pacific Coalition on Male Sexual Health (APCOM) has been working towards the improved sexual health and services for the community in Asia and the

Pacific. The MSM/TG Initiative aims to support networks and organisations through the provision of technical and advocacy support and assistance to foster coordinated approaches to advocacy and communications among network members.

Under the project, APCOM and AFAO forged partnerships with a range of national, regional and sub-regional networks and organisations, each working to fight HIV epidemics in-country and across the region. The networks involved are: Youth Voices Count (YVC), Asia Pacific Transgender Network (APTAN), Islands of Southeast Asian Network on Male and Transgender Sexual Health (ISEAN), Pacific Sexual Diversity Network (PSDN), Purple Sky Network (PSN), Myanmar MSM Network (MMN), and Viet Community Development Ltd. (VCDL).

The MSM/TG Initiative also promotes collaboration among the networks by creating a mechanism to share information from the region with the sub-region and, ultimately, with the country and community level, and vice versa. This includes the sharing of information such as policies, guidelines, media releases, and the documentation of successful approaches.

## Reporting and communications tools

One of the key elements of this project is the Rapid Assessment Apparatus ('Rapid App'). This is a reporting tool which assesses the strengths and needs of the networks against eleven essential criteria: governance; finance and administration; staffing; resource mobilisation; partnerships and networking; membership; program design and management; technical capacity; advocacy; communication;

and strategic information. APCOM and AFAO engage each community network in conversations that encourage them to reflect on daily achievements and progress, as well as areas where improvement is needed. Through this process, APCOM and AFAO can identify any gaps where additional technical and advocacy support for each network may be required, at the same time as areas where additional capacity development is required.

A regional analysis report presenting some of the findings of this work will be published and launched during the 2014 International AIDS Conference. The report summarises and analyses the common organisational strengths and weaknesses and puts emphasis on which programmatic areas the organisations should focus on.

One of the strengths presented is that the networks have a good representation of key affected populations including MSM and TG people – as both members and board representatives.

One of the needs found was a lack of capacity within the networks to mobilise and apply for the resources that are crucial to accomplish the goals of any advocacy organisation. A tool that proved extremely useful in assisting network communications is the Dissemination Plan Template (D-Plate), designed to assist the networks, organisations and individual advocates to strategically and effectively communicate information to their partners, target audiences and other stakeholders. The D-Plate template assists advocates to successfully identify and deliver key messages that are consistent with sub-regional, national or local issues that they wish to address through their organisational work.

Using the D-Plate template, the networks involve members and staff

in a discussion to agree on one or more advocacy messages that they wish to pursue. Being inclusive from the beginning of the process, the dissemination activity promotes co-operation within the network. Through these discussions a range of strategic decisions are made, such as identifying the most appropriate individuals to deliver particular advocacy messages and designing the best dissemination activity for this specific audience.

## Improving access to information

### Translating key documents

Another way that APCOM is assisting to build an enabling environment that assists the sub-regional and in-country networks to build capacity and increase the effectiveness of their advocacy initiatives is to make key documents about HIV in the region more accessible by translating them into local community languages.

English is the main language used in cross-country discussions and in the development of high-level policy and research materials on HIV in the region, but it is not the primary language used by most of the countries in Asia and the Pacific. To increase access to these key sources of information, a range of documents – including APCOM policy briefs, country snapshots and multi-city reports – were selected by APCOM and AFAO to be translated into 11 different community languages: Burmese; Chinese; Khmer; Lao; Thai and Vietnamese for the Greater Mekong Sub-Region; Bahasa, Cebuano and Tetum for the ISEAN Sub-Region; French and Pidgin for the Pacific Sub-Region.

Myanmar Youth Stars (MYS) is one of the country networks in Myanmar that will disseminate the APCOM Policy Briefs. ‘Hurray! Burmese!’ was the excited remark of recognition from one of the MYS members when the Burmese translated Policy Briefs were delivered to them during the first City-Based Hidden/Positive MSM Consultation in Yangon, Myanmar.

### The Headlight series

Knowledge of the relevant issues for HIV testing, prevention, treatment, care and support programs is essential role for development of effective responses in the region, sub-region and in-country. Apart from translating key documents in full, the project also developed ‘bite-size’ summaries of key materials (*Headlight: Bite Size Briefs*) to further enhance networks’ and advocates’ understanding about particular subjects to improve their advocacy skills.

The *Headlight: Bite Size Brief* series presents high-level documents in simplified format, using easy-to-understand language summarising discussions and analysis on issues affecting the rights and health of key affected population across Asia and the Pacific. Making data and research on local HIV epidemics more accessible creates opportunities for communities to use the evidence-based approaches in their advocacy efforts. The Bite-Size Briefs form part of APCOM’s ‘Light Series’, which also includes *Spotlight* (which highlights community organisations and their responses to HIV), *Limelight* (which features specific individuals and their advocacy work) and *Highlight* (which profiles advocacy work on a specific issue).

## More than partnerships

The success of the project to date is evident in the strong linkages and pathways that have formed among the regional and sub-regional as well as the in-country networks. By regularly sharing feedback on strategic methodologies and action plans, channels for open and effective communication between network members have been established. This includes information flow between city-based networks and sub-regional and regional networks, in a process which sees diverse community groups working together.

An example is the Hidden/Positive Consultation in Yangon, Myanmar, where a number of networks of men who have sex with men, gay, lesbian and transgender communities are working together towards evaluating the HIV response of the city, each providing recommendations and filling in knowledge gaps. It was also an opportunity for the regional networks such as APN+ and YVC to collaborate with their country networks by providing useful information on people living with HIV and young men who have sex with men, and for the consultation formats.

A noticeable effect of this environment of open communication between what can be at times quite disparate community groups, is the improved confidence in dealing with each other. This environment allows for the free exchange of ideas and feedback, and increased level of coordination, towards achieving effective results.

The knowledge transfer from regional to sub-regional and/or regional/sub-regional to national level improves the capacity of the networks in the areas of policy analysis, advocacy and effective representation. This facilitates the engagement of the networks in the regional and national responses to HIV. The knowledge and capacity provided are essential elements in effective participation and representation.

**Inad Rendon is Advocacy Capacity Development Officer at APCOM.**

A regional analysis report presenting some of the findings of this work will be published and launched during the 2014 International AIDS Conference. The report summarises and analyses the common organisational strengths and weaknesses and puts emphasis on which programmatic areas the organisations should focus on.

# Mobilising men who have sex with men for HIV counselling and testing

By **Matthew Vaughan**

Matthew Vaughan looks at an innovative pilot project that aims to increase demand for HIV counselling and testing among regional networks of men who have sex with men.

HIV testing is a critical component of any successful response to the HIV epidemic. Throughout Asia and the Pacific, evidence shows that many people do not undergo HIV testing for fear of stigma and discrimination.<sup>1</sup> Disclosure of a person's HIV status can negatively impact many areas of a person's life, such as family relationships, status in the community and livelihood. In some settings in the region, testing is only available through government services such as public hospitals or public sanitation clinics. This can be problematic for men who have sex with men (MSM) and transgender women who fear disclosure of their identity, or have concerns about discrimination. Community-based testing and counselling programs clearly demonstrate that community-based approaches help reduce stigma and discrimination, encourage greater up-take of services, and ensure greater protection of human rights.<sup>2</sup>

At the Melbourne International AIDS Conference, Asia Pacific Coalition on Male Sexual Health (APCOM) will launch a regional report, *MSM and HIV Counselling and Testing (HCT) in Asia and the Pacific*. The report details HCT activities in the region that target men who have sex with men. The report is based on inputs from key informants in Australia, Bangladesh, Cambodia, China, Hong Kong, India, Indonesia, Lao PDR, Malaysia, Mongolia, New Zealand, Pakistan, the Philippines, Singapore, Thailand, Tonga and Vietnam, and puts forward the following key findings:

- Although current approaches such as direct and indirect models of outreach, HCT service provision, client retention, support networks and strategic partnerships have been very successful, scale-up of services is urgently needed to achieve comprehensive service provision in the region.
- The success of HCT and comprehensive service provision is dependent on the visibility, availability, accessibility, confidentiality and affordability of services. Dependable partnerships and collaborations with public and private organisations that effectively offer effective treatment, care and adherence to antiretroviral therapy (ART) support also add to the success of HCT services.
- Creative and innovative outreach messages are required to attract MSM to HCT services. These targeted messages need to be supported by the continuous upgrading of skills among non-government and community-based staff/volunteers in areas including professionalism and empathy, as well as technical skills.
- For comprehensive service provision to be offered, the availability of funding from local governments and international organisations must be made a priority.

The report findings were fed into the development of the WHO Consolidated Key Population

Guidelines, ensuring that the voices and experiences from grassroots organisations are present in this key global document.

## Generating demand for testing

Mobilising the MSM community and generating demand for HIV testing, as well as increasing existing testing rates has been a great challenge for the region, and APCOM is looking at an innovative ways to increase testing rates through targeted messaging using platforms that are currently underutilised.

Building on from the 2010 Multi-city MSM and Transgender (TG) Initiative, which had identified the need for city-based responses and increased data on younger MSM at much higher risk to HIV but less likely to access services, an innovative campaign was developed which could be replicated and adapted to other cities in the region – including the cities from the Initiative: Bangkok, Chengdu, Ho Chi Minh City, Jakarta, Manila and Yangon.

## TestXXX

The TestXXX campaign is a regional campaign targeting young MSM through social media to encourage them to access HIV testing.

To date, Bangkok has never seen a large-scale, well-coordinated MSM HIV testing campaign. Until recently, traditional prevention campaigns have focused on venue outreach for condom distribution and other behaviour change interventions using the peer face-to-face method in locations perceived to be 'high risk hot spots' such as bars, clubs, sex-on-premises venues and massage parlours.

### Test BKK – the pilot project

The first phase of this campaign is TestBKK – a pilot based in Bangkok. It was important that TestBKK complement the already existing services in Bangkok. As a regional organisation, APCOM's role is not to replicate existing local services, including those online. Thailand already had a popular website used by MSM called Adam's Love. There were also many community organisations working on peer-led outreach services, including the Rainbow Sky Association of Thailand, Bangkok Rainbow, and for HIV-positive MSM, the Poz Home Centre Foundation. Our aim for the campaign was to, where possible, encourage MSM to visit one of the existing MSM friendly clinics or services for additional information and to provide follow up for treatment, care and support.

TestBKK explicitly promotes four 'premium testing services'. These services were identified during the focus group discussions as friendly or sensitive towards gay men and MSM. They include two main clinical testing services, Thai Red Cross Anonymous Clinic and the Silom Community Clinic @ Tropical Medicine, along with two community-based testing services, Rainbow Sky Community Health Clinic (the National MSM Network's new community based testing facility) and SWING Outreach Clinic (for male service workers in Bangkok).

Another part of the rationale for this approach was that the specific messaging within the campaign could be tightly focused on HIV testing. Information did not need to be included on every topic, and the TestBKK website was able to offer specific information designed to be quickly viewed and digested by our readers. The information we offered

focused on the key elements of HIV testing including 'where to go', 'what to expect', 'the results', and 'staying safe'. Further information was provided via links to existing services.

### Having a clearly defined target population

Given the concentration of the HIV infections in young MSM, and the target groups of already existing peer outreach services, we decided to target young gay men (18–24 years) that regularly seek out male sexual partners online. Therefore, we wanted a message that was considered edgy and relevant to our target audience; it needed to be short, sharp and simple. After several trial slogans and utilising focus group discussions with the target group, we were able to refine the campaign title to something that was catchy and appealing to our target audience: SUCK. F\*#K. TEST. REPEAT.

During the planning and discussions, we were trying to think of concepts that would make TestBKK attractive to young Thai MSM. Obviously it had to be sexy; that was a given. However, considering we had a limited advertising budget, we wanted to ensure that it was a message that would be widely shared through social media. At the launch of this campaign, APCOM – a regional health and advocacy organisation – had limited recognition and reputation within the MSM community of Bangkok. Careful consideration had to be given to how to establish the TestBKK brand within the community. We partnered with a well-known group in Thailand, TRASHER, which hosts a monthly dance party that attracts between 700–1200 young people, mostly gay men. They are also quite well-known for their music parody videos, each of which has been viewed on YouTube

between 500,000 to 1,000,000 times. Given their experience and the shared target audience, their involvement was critical to the success of TestBKK.

### Maximising visibility

Serendipitously, as we were preparing to launch the campaign, it was drawing close to April and the Thai New Year, Songkran, was just around the corner. This is a festive time for all of Thailand, and has become a key event on the social calendar of the gay community also, with the gay centres of Bangkok like Silom, Ratchada and Or-Tor-Gor being packed for the three nights of the festival, attracting crowds of up to 20,000 people. At this time, Bangkok also becomes home to the well-known gCircuit parties, which attract approximately 10,000 to 15,000 gay men from all over Asia.

This made for the perfect time to launch our campaign. We approached the party promoters, who couldn't have been more willing to support the campaign activities such as condom provision, posters in high-visibility areas, and an information booth where party-goers could access additional condoms or information about emergency testing facilities over the Songkran period.

These community outreach messages were coordinated with online messaging through Facebook, generating social interest by posting pictures of evening events, people receiving TestBKK branded condom packages and engaging with the TestBKK campaign. Alongside testing promotion messages and banner advertising on mobile applications Grindr and Hornet, we reinforced the campaign slogan, drawing people back to the campaign website.

With the support of the National MSM Network, we were also able to mobilise a community outreach team. Teams of 8–10 people visited key community hotspots, wearing the campaign merchandise, and handing out free water-proof bags, temporary tattoos, condoms and information.

During the planning and discussions, we were trying to think of concepts that would make TestBKK attractive to young Thai MSM.

Obviously it had to be sexy; that was a given.

During the launch of the campaign, over a period of three days, the team handed out more than 50,000 units of campaign materials. This was certainly the biggest coordinated response that the Bangkok gay community had seen for many years.

## Results

With a successful launch and community mobilisation we had generated significant interest in the campaign; in less than a month the campaign website had attracted approximately 35,000 page views. The four videos released on YouTube ticked over 500,000 views and people were starting to engage with the campaign. The videos released by TestBKK have received national and international media attention from nineteen different news outlets including the Huffington Post, The Gaily Grind and Queerty.

While it is early days for the first phase of the campaign, already we have

received notification from the clinics they have seen an increase in numbers of MSM testing within the services offered by TestBKK.

The success of the TestBKK pilot – which will hopefully see the campaign rollout in other cities – really depends on how successfully the target audience engage with the campaign and share messages on social media with their peers. The involvement of the service providers to ensure quality and stigma-free services is also essential. The aim is to create an environment where young people will feel confident about accessing testing – and when they do test, ensuring that their first time testing experience will be a positive one.

In the longer term the campaign will also need to be sustained by the involvement of the local community organisations, as well as private sector partnerships in order to reach other young people who may not already be connected to the HIV organisations.

The campaign was not a one-off activity and needed to be sustained over a period of time to build the brand recognition and trust. This sustained effort needs adequate investment in all these areas to achieve a best result.

**Matthew Vaughan is Senior Programme Officer at APCOM.**

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**apcom.org**

**SUCK  
F\*#K  
TEST  
REPEAT**

**testBKK.org**

\*โดยใส่ถุงยางอนามัยและเจลหล่อลื่น  
\*with condoms and water-based lubricant

ไม่ว่าจะอมหรือเอา\* เราทุกๆ คนก็ควรที่จะตรวจ HIV เรามีข้อมูลที่จะช่วยคุณ ให้เข้าใจถึงการตรวจ

Whether you like to suck or prefer to fuck\*, we all need to get tested. We've got helpful, clear information for you.

**f** TestBKK **t** #TestBKK

# A Papua New Guinea–Australia HIV Research Partnership: generating new knowledge, building capacity and forging new friendships

By **Clement Manineng<sup>1</sup>**, **Dr David MacLaren<sup>2</sup>**, **Michelle Redman-MacLaren<sup>2</sup>**, **Rachael Tommbe<sup>3</sup>**, **Dr Tracie Mafile'o<sup>3</sup>**

1 Divine Word University, Papua New Guinea; 2 James Cook University, Australia; and 3 Pacific Adventist University, Papua New Guinea

Partnerships of mutual benefit are often forged to confront a common challenge. One such challenge is how to address HIV in Australia's nearest neighbour, Papua New Guinea (PNG). With a wide range of cultures, a largely rural population and a host of other development issues, PNG is a tough environment in which to conduct public health research. In order to overcome some of these obstacles, researchers formed a collaboration between three universities: James Cook University in Australia, and the faith-based Papua New Guinean Universities of Pacific Adventist University and Divine Word University. This article describes that partnership, outlines our research capacity building activities and describes how colleagues become friends while contributing to the national and regional HIV response.

PNG has over 90% of the Pacific region's HIV cases. The first case of HIV was identified in 1987 and, until recently, rates of HIV have been increasing rapidly.<sup>1,2</sup> A range of intervention measures have been sought by both Australia and PNG, to help control rates of HIV in PNG.

In addition to increasing testing, improving HIV treatment and making condoms more available, another approach being considered in PNG is male circumcision. Between 2005 and 2007, a number of international studies showed that the risk of HIV transmission during heterosexual sex was reduced by 50–60% when men were circumcised.<sup>3,4,5,6</sup> Following

these findings, the World Health Organization recommended that male circumcision be scaled-up in countries with high rates of HIV transmission among heterosexuals<sup>7</sup>, and where the majority of men remain uncircumcised<sup>8,9,10</sup>. These findings and the recommendation to scale-up circumcision rates sparked great interest in PNG, given its high rates of HIV primarily among the heterosexual population, limited traditional male circumcision practices and the lack of any national medical male circumcision program.

In the planning phase, this project carefully considered the challenges of conducting research into male circumcision for HIV prevention in PNG and decided that collaboration was the best approach. Researchers from James Cook University (JCU) in Australia had more experience and expertise in study design, data management and publication while researchers from PNG had more experience and expertise in interacting with local cultures, the logistics of data collection and local interpretation of study results. As found in other health research in the Pacific, the collaborative blending of these skills was fundamental to the success of the program.<sup>11</sup>

The sensitive nature of HIV and male circumcision was an obstacle in itself. Papua New Guineans do not talk openly about sex and so in initial stages, desensitising workshops were organised to practise data

collection techniques and improve data collection skills. In addition, our team was aware that language can be a daunting challenge for non-Papua New Guineans. The official language in PNG is English but the common, everyday language is *Tok-Pisin* and each of the 800 different cultural groups that make up PNG has their own language. The JCU researchers needed to be able to understand the meaning of conversations, and know what is the acceptable form of greeting and so on.

Apart from language, a mixture of religious backgrounds and diversities in geography, culture and beliefs adds to the complexities of public health research in PNG. In addition to that, the different rates of HIV across the country and limited health services means that any HIV prevention campaign involving male circumcision would need to be informed by local evidence. We therefore wanted to know how PNG people felt about male circumcision. Did they know that male circumcision had health benefits and could help prevent HIV? What were women's views and what were men's views? Do the views differ by religion or geographic region? We wanted to have answers to these questions and at the same time, we wanted to boost the capacity of PNG academics to be independent researchers.

While PNG academics were keen to undertake research, their experience with large HIV studies was limited. Apart from a few senior leaders, most



**Above:** HIV researchers from Divine Word University, Pacific Adventist University, National Department of Health of Papua New Guinea and James Cook University at the 'Technical Data Analysis and Writing Workshop', James Cook University, November 2012, funded by an Australian Leadership Award.

academics in PNG are not trained or sufficiently qualified to undertake independent research. Therefore, in addition to contributing towards HIV response in PNG, our project had a key focus on research capacity building and supporting PNG researchers to attain higher qualifications. This allows skilled and qualified PNG researchers to not only lead local and regional HIV research but also contribute to quality of teaching and learning at PNG universities.

A 'learn by doing' approach was taken to build research capacity. Potential lead researchers at PNG universities were identified and given lead roles early in the collaboration. Many other potential PNG researchers were involved and most of them participated in various capacity building activities. These included workshops on data collection, data analysis and writing for

publication, presentation at scientific meetings and participation at a national policy forum.

Several PNG researchers from our group are now undergoing masters and doctoral level studies at universities in PNG, Philippines and across Australia. This improvement in research capacity is one step in the process of enabling PNG to improve the search for workable solutions to the HIV epidemic and other development issues.

Our study needed to progress within a 'give and take' setting – an avenue for mutual benefit. JCU researchers led the team in study design and capacity building and PNG researchers provided the enabling environment for data collection and to make data understandable. All three collaborating universities hosted workshops to improve research capacity and to

explore the research topic. We went on to present results in numerous local, national and international conferences and forums<sup>12-19</sup> and produced a comprehensive paper published by *BMC Public Health*, Foreskin cutting beliefs and practices and the acceptability of male circumcision for HIV prevention in Papua New Guinea<sup>20</sup>. We also published a paper on the processes we used to conduct the research together, *Researching male circumcision for HIV prevention in Papua New Guinea: a process that incorporates science, faith and culture*.<sup>21</sup>

Looking back, the collaboration has been a huge success. Involvement of PNG researchers, some of whom had lead roles, was a winning factor in recruiting study participants, collecting and analysing data and writing for publication. Additionally, the opportunity for capacity building

provided by the study was a rare achievement for a research project. Less experienced researchers were up-skilled to conduct research independently. Two of the PNG academics are currently lead investigators on a number of HIV research projects in PNG. A JCU member of the team has also enhanced her research skills and is currently in the final stages of her doctoral studies about women and HIV in PNG.<sup>22</sup>

While this partnership received its share of positive comments, one most notable was a remark uttered by a respected senior academic from one of the collaborating PNG universities. In his comments during a feedback presentation, he mentioned that this project was one of very few that not only included capacity building as a vital component of its research activities but actually fulfilled those capacity building plans. He reiterated that future research in PNG would do well to follow the same lines with emphasis on capacity building.

On a people-to-people level, something else eventuated that is important to mention. Over the life of the project, lasting friendships were formed between researchers. While our initial four year study (2010–2013) to investigate the acceptability and feasibility of male circumcision for HIV Prevention in PNG has ended, we continue to collaborate across a number of follow-up studies that have emerged. Work on these studies will further strengthen existing relationships. The collaborating researchers, especially the lead partners do not see themselves as being mere colleagues; they have gone beyond that, seeing themselves now as friends. One would frequently hear collaborators offer to their travelling colleagues to, 'come and stay with us at our house'. That kind of offer comes from relationships that have grown roots, relationships that will care for the shortcomings and triumphs of its partners in the years to come.

The direct consequence of links like these is a solid regional partnership that can help improve the HIV

response and other development issues for PNG, Australia and surrounding Pacific island nations.

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# Sex worker organisations' partnerships and collaborations for capacity development

By **Maria McMahon**

Scarlet Alliance, the Australian Sex Workers Association, is the national peak body representing sex workers and sex worker organisations in Australia. Formed in 1989, Scarlet Alliance is a community-based organisation. Through its objectives, policies and programs, Scarlet Alliance aims to achieve equality, social, legal, political, cultural, health and economic justice for past and present sex workers.

Within the global HIV epidemic, sex workers are defined as a key affected population. The majority of HIV infections are sexually transmitted, putting sex workers and their clients at heightened risk of acquiring HIV. Sex workers not only experience the impacts of HIV, but also experience increased stigma and discrimination on the basis of their occupation and real or perceived HIV status, reduced human rights and a lack of access to health services.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) states:

*'To date, the HIV response has devoted insufficient attention and resources to efforts to address HIV and sex work, with less than 1% of global funding for HIV prevention being spent on HIV and sex work. The epidemiological data on HIV infection rates among sex workers and their clients reflects the failure to adequately respond to their human rights and public health needs. Recent studies continue to confirm that in many countries sex workers experience higher rates of HIV infection than in most other population groups.'*<sup>1</sup>

UNAIDS also says in *Principles of Effective HIV Prevention*: 'Community participation of those for whom HIV prevention, treatment, care and support programmes are planned is critical for their impact.'<sup>2</sup> Sex workers need to be central within a strong HIV response.

The centrality of sex workers within the HIV response is imperative and includes activities to support and strengthen sex workers' organisational capacity, leadership and advocacy. Just as the Australian response has included sex workers within the partnership addressing HIV, so too should sex workers be included in the design and delivery of responses in our region.

Scarlet Alliance has 25 years' experience within the Australian HIV response of significant program design, implementation and evaluation experience, as well as advocacy for sex worker rights. The Regional HIV/AIDS Capacity Building Program, funded by Australian Aid, links nine Australian organisations with counterparts in the Asia and Pacific regions to develop the capacity of the most affected communities and their peer-based organisations to actively participate in national and regional responses to HIV. Scarlet Alliance's project titled *Sex Worker Organisations' Collaboration for Strengthened Advocacy and Partnerships* includes activities to support and strengthen sex workers organisational capacity, leadership and advocacy.

In a project evaluation report, one sex worker organisation said:

*'HIV has been with us for 30 years already. Social and legal changes are not short-term projects but are a long journey. Leadership on this journey is not static but is more like a relay where the task to reform must continually be passed along to emerging leaders. The Capacity Building Program with Scarlet Alliance is one avenue where emerging and young sex worker leaders can be mentored and given opportunities to stand up. Without support how can we grow new leadership and continue the journey?'*<sup>3</sup>

Scarlet Alliance works in capacity development partnerships in the Asia and Pacific regions, including partnerships with Friends Frangipani in Papua New Guinea, and with Scarlet Timor Collective in Timor Leste. In addition, the project brings the partners together for strategic partnership building activities around international forums such as the International Congress on AIDS in Asia and the Pacific (ICAAP) and International AIDS Society (IAS) conferences.

The capacity building approach is unique, involving a mentoring partnership between our peer sex worker organisations. This approach varies dramatically from provision of technical advice or short-term training. The approach is a long-term commitment to ensuring the sustainable development of a sex worker organisation with the capacity to govern, consult and represent sex workers and work within the unique set of barriers that affect sex worker organisations. The approach brings with it a network of support as sex workers are linked into national, regional and international sex worker networks.

*'The networking of sex worker groups from different countries empowers us. We have common ground, common problems, and a common destination.'*<sup>4</sup>

Scarlet Alliance adopts an approach that includes 'learning by doing'. Capacity is built and held by the individuals, the sex worker community and thus the organisation on an accumulative experiential basis, and retained within the guiding documents, policies, records and systems. Rather than developing a dependent relationship, the organisation knows its capacity and genuine potential at any time, as a function of this lived experience and retained infrastructure.

Project partners note that leadership growth takes time to achieve, yet all report a boost in confidence and competence as a result of project activities, as illustrated in these quotes from project participants:

*'The forum really built my capacity and our organisation as well, we practiced chairing meetings, taking minutes – it had a different feel about it, a good feeling, gave me confidence to stand up and talk, especially in international groups.'*<sup>5</sup>

*'Now I have the guts to talk for my fellow sex workers and talk for their rights.'*<sup>6</sup>

*'I stood up; I had the confidence to speak with donors. We need our voice to be heard, we face it, we feel it, we know what it's like. It gave me the courage and confidence to stand up strong and talk public.'*<sup>7</sup>

The activities create a rare space for sex workers to drive their own agenda, bring a boost in confidence, competence and self-determination. The skill sharing within a sex worker only setting is invaluable, and project partners are encouraged to articulate and advocate their agenda.

*'We can share the (sex worker) language between us, ideas, feel comfortable to talk out and share. If other stakeholders attended this meeting, we would not feel good to share.'*<sup>8</sup>

*'Because of our partnership with Scarlet Alliance, how to develop/ create our capacity to raise awareness of our problems we face every day as sex workers, our human rights, sexual abuse, violation, because we understand our rights, we are more confident. It means we can meet with stakeholders and go into a relationship with them.'*<sup>9</sup>

The Project strengthens regional networking and relationships, enhances sex worker organisations' day-to-day efforts to champion sex worker rights, and contributes to community solidarity and collaboration across the region.

*'It is helping us to stand up strong and talk out. We are feeling strong to fight for our rights too – we see other sex work organisations can do this in another country, and this strengthens us.'*<sup>10</sup>

Sex worker advocacy actions were cohesive and delivered messages on enabling legal frameworks, including the call to decriminalise sex work, that were highly visible within regional forums and related media. Sex worker representatives clearly identified issues and called for specific changes through their advocacy work, and connected with key stakeholders through regional forums. The key message that decriminalisation will best support sex workers responses to HIV, has reached non-government organisations, governments, the World Health Organization (WHO), UNAIDS and the United Nations Population Fund (UNFPA) and is now consolidated into national, regional and international strategies and policies.

Regional forums are where significant progress in terms of sex worker advocates participating effectively takes place. Scarlet Alliance provides support and mentoring for partner organisations to engage in opportunities, select and prepare representatives, develop activity proposals, develop advocacy, travel and participate. The international conferences provide sites for key learnings and collaborations.

Importantly, the project enables feedback from international events by sex worker advocates to the sex worker community and other stakeholders in-country. This can reorientate key stakeholders as they see sex worker issues' profile raised and understand better how sex workers national demands fit within the global HIV response. There is more leveraging possible given the "match" between national and international advocacy messages and policy environments.

*'I was invited to a civil education workshop to talk a little bit about ICAAP. I was confident to share with my community the purpose of it and it was an eye opener for them since they didn't know about it.'*<sup>11</sup>

*'... we became members of National AIDS Commission; we have more recognition of our position from*

*government because we have been members of international events.'*<sup>12</sup>

Sex workers in the region continue to build their presence and effectiveness at national and international levels, and are clearly taking their place within the response. Sex workers within the partnerships have gained a stronger voice in the national HIV response, and within regional and international forums. The capacity building work is now more important as countries realise that sex workers need to be at the table, advocating on their issues and needs in order to have an effective HIV response.

**Maria McMahon is International Program Manager at Scarlet Alliance.**

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## TREATMENT BRIEFS

## SEMINAL US REPORT ON TREATMENT STRATEGIES FOR OLDER HIV PATIENTS UPDATED ON HIV-AGE.ORG

On May 28, 2014 the American Academy of HIV Medicine (AAHIVM), the AIDS Community Research Initiative of America (ACRIA) and the American Geriatrics Society (AGS) released a revised version of the report, *Recommended Treatment Strategies for Clinicians Managing Older Patients with HIV*.<sup>1</sup> Originally published in 2011, the report is a key resource for managing HIV in older patients. Almost half of the report's chapters have been updated, and are accessible via an interactive website at: <http://hiv-age.org>

The report and website form part of the HIV and Aging Consensus Project, developed to assess how the presence of both HIV and common age-associated diseases alter the optimal treatment of HIV, as well as other co-existing medical conditions.

'We are learning more and more everyday about how to best treat HIV in aging patients,' said Jonathan Appelbaum, Medical Director of the HIV and Aging Consensus Project. 'As new research and clinical studies emerge, we are committed to reflecting those learnings in our treatment strategies to ensure best practices among all HIV care providers. In Australia, ASHM provides a commentary on the several international antiretroviral guidelines (including those produced by the DHHS). This resource may be a useful supportive text for use in the Australian context.'

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## LOW VITAMIN D CONCENTRATIONS ASSOCIATED WITH POOR CLINICAL AND VIROLOGICAL OUTCOMES AMONG PEOPLE STARTING HIV THERAPY

Low vitamin D concentrations are associated with an increased risk of HIV disease progression among people starting antiretroviral therapy, investigators report in the online edition of *The Journal of Infectious Diseases*. Virological failure also had an association with low vitamin D levels at the start of therapy, and there was evidence suggesting a relationship with between vitamin D levels and immunological outcomes. The study was conducted in eight low- and middle-income countries and the US. The authors believe that studies exploring the impact of vitamin D supplementation on HIV treatment outcomes are warranted.

Concentrations of vitamin D are related to exposure to sunlight, latitude, season and skin pigmentation. The vitamin is important to a healthy immune system. Several studies involving people living with HIV have shown a high prevalence of low vitamin D concentrations.

However, few studies have examined the relationship between low vitamin D concentrations at the initiation of antiretroviral therapy and clinical outcomes. The connection between baseline vitamin D levels and virological and immunological outcomes is unexplored.

Data collected during the PEARL (Prospective Evaluation of Antiretrovirals in Resource Limited Settings) study provided information for investigators to explore the relationship between low baseline vitamin D levels and treatment outcomes.

Almost half (49%) of all participants in the study had low vitamin D concentrations at baseline. Prevalence of low vitamin D varied between countries, ranging from 27% in Brazil to 78% in Thailand and 72% in India. Prevalence was 92% among African-Americans in the US.

After controlling for country and HIV treatment regimen, the factors significantly associated with low vitamin D were race, season of sampling (winter/spring), high or low body mass index (BMI) and lower HIV viral load.

The investigators cite other studies showing it is 'biologically plausible' that low vitamin levels would increase the risk of poor clinical outcomes.

Low vitamin D at baseline more than doubled the risk of virological failure. The authors note that theirs is the first study to identify vitamin D as a factor in the virological outcomes of therapy.

There was also evidence suggesting that low vitamin D increased the risk of a poor CD4 response to treatment. However, there were too few cases for this to be proved.

'The associations found in this paper raise questions of reverse causation: does advanced HIV disease cause low [vitamin D] concentrations; or, is low [vitamin D] concentration a general marker for poor health,' write the authors. 'The fact that this was prospective and that severely ill persons were excluded from the study makes this unlikely. Also, [vitamin D] concentrations were comparable to those found in studies of non-HIV infected persons in similar populations.'

The investigators believe their findings support the concept of vitamin D supplementation as an adjunct to HIV therapy, concluding 'a well-designed clinical trial is needed.'

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