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Submission to the Inquiry into Immigration Detention in Australia - July 2008

The Australian Federation of AIDS Organisations (AFAO) is the peak body for Australia's community sector response to the HIV/AIDS epidemic. AFAO is charged with representing the views of its members: the AIDS Councils in each state and territory, the National Association of People Living with HIV/AIDS, the Australian Illicit and Injecting Drug Users League, and Scarlet Alliance - the national organisation representing sex workers. AFAO advocates for its member organisations, promotes medical and social research into HIV/AIDS and its effects, develops and formulates policy on HIV/AIDS issues, and provides HIV policy advice to the Commonwealth Government. The HIV/AIDS Legal Centre (HALC) is a community legal centre specialising in HIV related legal matters. Based in Sydney, HALC provides legal advice and services to individual clients, and based on that casework and other research, provides policy advice and analysis on HIV related legal matters.

AFAO and HALC congratulate the Joint Standing Committee on Migration for holding an Inquiry into immigration detention in Australia, and broadly commend the Inquiry's terms of reference. Fortunately, there have been significant improvements to immigration detention practices over the last few years, in particular, releasing all children from detention and the consideration and rolling out of options other than institutionalised detention for those undergoing the immigration assessment process. This submission will, however, limit comment to a number of issues that directly impact the public health management of HIV/AIDS and the treatment of HIV positive people. It argues that although significant improvements have been made in relation to the delivery of health services, more needs to be done.

At the outset, it is important to state that rarely has AFAO, in its position as the peak body for Australia's HIV community sector, had such difficulty in compiling data on a particular issue. Similarly, HALC faced significant barriers when attempting to advocate for an HIV positive client held in Villawood Detention Centre last year. This situation likely arises from a combination of intersecting factors including the relatively low numbers of HIV positive people held in detention over the last decade, an apparent lack of HIV specific referral pathways, and the government's culture of secrecy surrounding immigration detention. What you will no doubt glean from the above is that this submission

is based on limited information, which is precisely one of the points it seeks to address.

Immigration

HIV infection affects immigration in numerous ways. Firstly, it impacts the likelihood of successful application for permanent resident status.[1] All applicants for permanent visas, including the main applicant, spouse and any dependants (whether or not the spouse and dependants are included in the visa application) must be assessed against the health criteria specified in Schedule 4 to the Migration Regulations. For those aged 15 years or older, that includes being tested for HIV infection.

Being diagnosed HIV positive usually means an applicant fails the health criteria, and the application is rejected. In certain cases, applicants may appeal as DIAC has the discretion to waive the applicable health requirement in cases involving interdependency, spouse, child and protection visa applications. An appeal usually considers compelling and compassionate factors. Waivers are occasionally granted. Conversely, in some instances HIV infection (and its implications) has been a convincing reason for the granting of asylum. AFAO and HALC have broad experience and have previously undertaken significant work in this casework and policy area. Less is known about the impact of HIV on those who are detained.

HIV infection is relevant to immigration detention in a range of ways including practices of HIV testing, the management of complex treatments (including patient adherence to those treatments), and risk of transmission within the detention environment, as well as issues arising in transition from detention, whether into the Australian community or repatriation. These issues will be considered below.

Information about the number of HIV positive immigration detainees is not publicly available.[2] Given the importance of maintaining confidentially and the highly politicised, volatile nature of debates around immigration and also around HIV, that practice is not at issue in this submission.

Anecdotally, it appears few HIV positive people have been held in immigration detention in the last few years, although some certainly have. A 2001 study of 7000 people in detention in South Australia and Western Australia[3] found four people tested positive for HIV (although two tests were inconclusive)[4]. The submission from allied health care professionals to HREOC's Inquiry into Children in Immigration Detention includes a disturbing case study of an HIV positive detainee.[5] And HIV positive detainees from Villawood have also presented at the HIV/AIDS

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[1] Those applying for short term visas such as a tourist visa and ... are not required to undertake HIV testing.
[2] It is hoped the Department of Immigration actually records and monitors this issue.
[3] King, K. & Vodicka, P. (2001) 'Screening for conditions of public health importance in people arriving in Australia by boat without authority', MJA, 175, 600-602
[4] Suggesting that at least at that time, the rate of HIV prevalence was lower than in the general community.
[5] Alliance of Professionals Concerned about the Health of Asylum Seekers and their Children, "Submission to Human Rights and Equal Opportunity Commission Inquiry into Children in Immigration Detention", May 2002 at http://www.spareroomsforrefugees.com/alliance_inquiry.pdf

Legal Centre and Albion Street Centre in Sydney. Körner's 2005 study on HIV positive people from culturally and linguistically diverse backgrounds identified 17 HIV positive migrants whose serostatus impacted their immigration assessment, although it is not clear how many of these people were held in detention.[6] While it appears few HIV positive people have been held in detention, it is vital that low numbers do not mitigate against the development and implementation of best-practice standard procedures, protocols and referral pathways for the treatment of HIV positive detainees.

Lack of partnership approach

Australia's response to HIV/AIDS is guided by the National HIV/AIDS Strategy, now in its fifth incarnation. The Strategy acknowledges that:

> The foundation of Australia's successful response to HIV/AIDS has been the close collaboration of affected communities, all levels of government, and the health and research sectors. Efforts by States and Territories and community-based organisations have been focused, mobilised and given direction through a series of national strategies, with strong Australian Government support.
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> Central to Australia's response in all of these strategies has been the notion of partnership between affected communities, governments, researchers, educators, and health care professionals, as well as the adoption of innovative education and prevention initiatives. This partnership has fostered a significant degree of policy and program integrity across government, community, researchers and service providers, ensuring the early and effective response to emerging changes in the epidemic. Furthermore, strategies have been firmly based on evidence. The success of Australia's partnership based response is recognised worldwide.[7]

Unfortunately, those with HIV in detention are unlikely to be part of affected communities (ie. communities drawn together by the impact HIV has had on their lives), and community based organisations and researchers have largely been locked out of immigration detention. Without such a partnership, AFAO and HALC remain concerned about the treatment and experiences of this greatly disempowered, highly marginalised group: HIV positive immigration detainees.

Lack of public scrutiny

The provision of detention services, which are ostensibly outsourced, lacks transparency by virtue of commercial confidentiality. The two consecutive

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[6] Henrike Körner, "HIV and migration: two major uncertainties for people from culturally and linguistically diverse backgrounds", Social Research Issues Paper 4, National Centre in HIV Social Research, Sydney, 2005 at http://nchsr.arts.unsw.edu.au/pdf%20reports/SRIP04.pdf

[7] Australian Government, *National HIV/AIDS Strategy 2005-2008,* Australian Government, *Canberra, 2005 at* http://www.health.vic.gov.au/hivaids/5th_hiv_strategy.pdf

reviews by the Australian National Audit Office into DIAC's management of detention centre contracts (Parts A & B) revealed significant problems in the governance and project managements arrangements for the administration of detention and health service contracts. Fortunately the most recent review notes 'significant improvements' in the early management of the tendering process. That being said neither the contracts nor the day to day operation of the centres are subject to public scrutiny.

AFAO and HALC welcomed the 2006 establishment of the Detention Health Advisory Group as an important step towards working in a more open and accountable manner, and the delivery of improved detention health standards. The development of the Detention Health Framework and Health Standards has the potential to significantly impact health service provision in relation to HIV/AIDS. We await more news of the development of a process for ongoing evaluation and accreditation of health service providers, an area of particular interest given the specialised nature of HIV/AIDS treatments. The Detention Health Data Set is also an important step towards delivering a quality health care response that is evidence based. These mechanisms, and others developed by the Detention Health Advisory Group, mark a significant improvement on the Department's broad commitment to 'provide health services consistent with services available within the general Australian community'. While an admirable sentiment, such a broad motherhood statement alone has minimal effect on day to day delivery of health care services.

AFAO has a particular interest in the development of the Infectious Diseases Sub-Group. Now 'concluded' but waiting to hear from DIAC what they did.

Provision of HIV Testing and Discussion (Counselling)

The policy for HIV screening adopted by immigration detention health service providers is in line with the National HIV/AIDS Strategy 'Revitalising Australia's Response 2005 – 2008', and is based on the six National Guiding Principles. The policy requires that all people entering detention be offered screening for a range of conditions, including non-compulsory, voluntary and confidential testing for HIV with associated pre and post test discussion[8].

Although the first principle of Australia's National HIV Testing Policy 2006[9] is that confidential voluntary testing with informed consent is fundamental to Australia's HIV/AIDS response, it goes on to provide that there are some circumstances where mandatory or compulsory testing may be appropriate in situations where people may not participate in certain activities or access

[8] Previously referred to as 'pre- and post-test counselling'. The current Australian HIV Testing Policy states, "The 1998 National HIV Testing Policy recommended that the terms 'HIV test discussion' and 'post-test counselling' replace 'pre- and post-test counselling'. The purpose of recommending this change in terminology was not in any way to diminish the role of this discussion, but rather to acknowledge the increasing complexity of factors that may be involved in these discussions. Further, the complexity of discussion will vary from person to person depending upon their risk factors and experience (if any) of previous testing."

[9] at http://www.health.gov.au/internet/main/Publishing.nsf/Content/F4F093E1E22A7478CA256F1900050FC7/$File/hiv-testing-policy-2006.pdf

certain services unless they agree to be tested. One of those situations is testing for immigration purposes.

Although people are not automatically tested for HIV when entering detention, most are or have been tested as a compulsory requirement of their assessment for permanent residency. This requirement has meant that some migrants become aware of their HIV status only through this process: a very difficult circumstance in which to learn one is HIV positive.[10][11]

Körner's study[12] raises an issue of concern relating to the delivery of pre and post test 'counselling' (now referred to as 'discussion' – see footnote 8)[13]. It is based on interviews with 17 HIV positive people who arrived in Australia between 1994 and 2000, and were diagnosed with HIV between 1994 and 2003. All applied for permanent residency while in Australia. Fourteen had been diagnosed in Australia as a result of immigration health screening. Significantly, despite pre and post test discussion having been an integral component of HIV testing since the early 1990s, no one in Körner's study recalled any pre or post test discussion.

The issue is not simply that pre and post test discussion should be provided. Perhaps some form of pre and post test discussion were provided, but this was clearly inadequate. The patient was left feeling isolated with limited understanding of their condition and its impact. As the terms 'discussion' and 'counselling' suggest, what is required is more than the straightforward provision of information[14]. For pre and post test discussion to be effective, dialogue must be responsive and engage with the patient's understanding of HIV within their broad cultural context: a context that in this instance includes not only their frequently limited knowledge of HIV/AIDS gained in their country of birth (including misconceptions that an HIV diagnoses means certain death and that it is ostensibly a disease indicating low morals), but also their experience of immigration uncertainty (ie. possible repatriation) and detention. The situation in which people are tested and receive their diagnosis, and then engage in discussion has the potential to significantly affect their need for information and understanding of information provided. Of note, Körner states that 'for those whose application for permanent residency had been rejected, waiting for the outcome of their appeal, the uncertainty of their migration status was [considered] a bigger problem than their HIV status'[15].

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[10] This may be because they have arrived in Australia legally on a short term visa not requiring HIV testing, and have overstayed their visa or sought to change visa category, or have they have arrived by boat seeking asylum. Some HIV cases diagnosed in detention are also likely to be of people who arrived legally in Australia, and seroconverted while here.

[11] This submission is reiterated by the NSW Community Relations Commission's submission to ...., which states " Whilst HIV tests are performed overseas on individuals 15 years old and above, there are small numbers who have been found to be HIV positive soon after arrival". Community Relations Commission for a Multicultural NSW, 'Submission to the Parliament of Australia Senate Legal and Constitutional Committee Inquiry into the administration and operation of the Migration Act 1958', August 2005 at http://www.aph.gov.au/senate/committee/legcon_ctte/completed_inquiries/2004-07/Migration/submissions/sub232.pdf

[12] Henrike Körner, at 12 above.

[13] and that terminology will now be used in relation to Körner's work

[14] there has in fact been some debate about the appropriateness of the term 'counselling' as .... however retained to add weight ...

[15] Henrike Körner, at 12 above.

* waiting on DIAC confirmation re: where HIV testing done and by whom

Recommendation 1: That HIV testing procedure be reviewed to ensure that pre and post test discussion is provided in a form that adequately informs and supports patients in detention.

Recommendation 2: That a means to centralise HIV testing of immigration detainees is considered, so that testing and treatment may be provided by staff with appropriate expertise in servicing this specialised group.

Recommendation 3: That all HIV positive detainees be held in one urban location, and their medical care be centralised through one health care agency (unless that practice involved moving them from a location in which they were living and receiving treatment prior to detention, or in which their family and support network are living).

For example, if all HIV positive detainees were held in Sydney, their health care might be centralised through Albion Street Centre, (a facility of the South East Sydney and Illawarra Health Service) a WHO centre what is the full description? and the only major Australian community based, multidisciplinary centre dealing exclusively with HIV and Hepatitis C clinical management, counselling, research, prevention and education.

Provision of Treatments

The treatment of HIV infection is highly specialised. Generally HIV treatment medications can only be prescribed by specialists or general practioners who have satisfied National Standards for Certification of Community HIV s100 Prescribers. General practitioners must have experience managing a high HIV caseload, and must undertake specific training and ongoing accreditation. The accreditation process enables greater understand of guidelines governing the use of antiretroviral therapy, different treatment regimens, associated risks and benefits, as well as the factors influencing patients' treatment decisions and therapeutic outcomes. Training also highlights the challenges faced by patients during therapy and examines various approaches to maximizing adherence (a crucial issue in HIV treatment), the management of toxic reactions to antiretroviral therapy, and the impact of co-morbidities on patient management.

While for some conditions a minor lapse in medication provision may be of little consequence, in the case of HIV, lapses of just two days/ month can have potentially serious deleterious effects. Ninety to ninety five percent adherence to treatment is required for maximum efficacy of anti-retroviral drugs. Poor adherence is associated with poor virological and immunological response and development of drug resistance in the patient.[16] That means, poor adherence can trigger a situation where not only are the 'symptoms' not effectively

[16] Anna Pierce, *HIV Management in Australia: a guide for clinical care*, Hoy and Lewin ed, ASHM, Sydney, 2003, p.60.

controlled but particular treatment regimes will consequently be permanently ruled out. The number of treatments for HIV is, of course, limited.

Case study of 'A'[17] – Man with advanced HIV, with resistance to many anti-retroviral drugs (2005/2006)

When 'A' presented for advice at the HIV/AIDS Legal Centre he was being held at Villawood Detention Centre. 'A' had advanced HIV with resistance to many anti-retroviral drugs. He also had a number of other severe medical conditions requiring treatment and medication, including gout and ischaemic heart disease.

Provision of medical treatment - 'A''s specialist physician prescribed some 7 to 9 pills to be taken at separate intervals throughout each day. All had to be take to affect treatment. Some of those medications required refrigeration.

'A' reported that at times his medications were 'dispensed' by nurses pushing a box of pills through the door and letting him take what he wanted. The nurses did not seem to know or care which pills he took. 'A' questioned whether the medications had been refrigerated as they were not cool when they got to him. Despite adherence to the full regimen being a crucial component of effective treatment, on at least one occasion 'A' was not provided with his HIV medications over a period of three days.

On at least one other occasion, 'A' was also denied prescribed medication for his gout conditions over a period of three days. He was also provided with inadequate pain relief medication during that time. 'A' became extremely frustrated and distressed, a situation made worse by its potential impact on his ischaemic heart disease and poor heart condition.

A reported that in more than one instance, there were problems, ie. delays renewing 'A''s medications, which again caused him anxiety and distress.

Provision of medically appropriate diet – 'A' was prescribed a reduced fat and sugar diet to treat his heart condition and improve his general health. His treating specialist was concerned about elevated triglyceride levels in his blood at various times during 'A''s detention at Villawood. 'A''s HIV medications complicated normal control of blood triglycerides, making dietary control of fats and sugars more significant to controlling and treating his heart disease condition. At one point, the treating specialist advised this specific problem had become more dangerous than 'A''s advanced HIV condition, and was a serious threat to his health.

Unfortunately Villawood staff seemed to have little to no capacity to provide 'A' a low fat, low sugar diet, and high triglyceride levels were an ongoing problem during his detention.

Inadequate exercise facilities - Nil to limited exercise facilities were available to 'A' while detained in Villawood despite exercise being

[17] Client of HIV/AIDS Legal Centre held in Villawood Detention Centre

important in the treatment of his ischaemic heart disease and other complicating health issues. 'A' was without access to exercise equipment or adequate space to walk and exercise.

The case study of 'A' raises a number of issues:

- **Inappropriate and dangerous administration of medications**

Although 'A' was able to access a specialist physician who prescribed appropriate treatments, Villawood staff failed their duty of care and those treatments were not appropriately administered and distributed. Sloppy administration of dosage is particularly surprising in an environment where drug hoarding is likely to be an issue, as it is in most institutions.

- **Lack of referral for medical care**

When 'A' complained that the painkillers staff provided for his gout were insufficient, medical referral should have been made.

- **Inaccessible staff and lack of referral**

When HALC attempted to intervene on 'A''s behalf, the solicitor was unable to contact relevant staff. Those who were contacted responded that the issue raised was not their job and not their concern. Similarly, HALC was also unable to gain confirmation from Villawood staff that appropriate refrigeration of medications was practiced.

- **Possible inappropriate housing**

HALC was unable to discover why 'A' was housed in the security wing despite no relevant violent record or any complaints of non-compliance or misdemeanours of which HALC was aware. This raised the disturbing possibility that 'A' may have been housed in the security wing for reasons related to his HIV status.

- **Systemic lack of transparency and accountability**

HALC was unable to identify a clear line of authority and accountability in relation to the provision of medical treatments, with conflicting information provided about whether the Department or its outsourced health service provider was accountable.

Recommendation 4: That procedures for managing and dispensing medications be reviewed and improved to ensure basic standards of medical care are met (and opportunities for drug hoarding minimised). For example, prescriptions must be filled in advance of their requirement and distributed accordingly; and temperature sensitive medications must be appropriately housed and transported.

Recommendation 5: That pain management be recognised as an area of medical expertise, and that if detainees are unsatisfied with pain relief provided, additional medical referral be made as soon as is needed.

Recommendation 6: That guidelines be drafted and training undertaken to ensure all staff understand that upon receiving an external inquiry, they have a duty to identify the departmental officer or other staff responsible for particular practices/areas, so that external inquiries may be answered in an expedient manner.

Recommendation 7: That publicly available guidelines be drafted for the housing of HIV positive detainees. As noted in recommendation 3, ideally all HIV positive detainees would be held in one urban location (unless that practice involved moving them from a location in which they were living and receiving treatment prior to detention, or in which their family and support network are living).

Immigration detainees' ability to access medical treatment is affected by their Medicare status. Currently those on certain temporary visas are ineligible for Medicare, although it is hoped this may soon change. Without PBS subsidy, HIV anti-retroviral medications are prohibitively expensive and well outside the affordability of most Australian citizens, let alone people in detention. Specialist HIV centres such as the Albion Street Centre have developed means to treat non-Medicare eligible patients with appropriate anti-retroviral medications. It is vital that all HIV-positive detainees be referred to specialist HIV treatment centres with expertise in managing Medicare ineligible patients.

Körner's study considered the issue that those on antiretroviral treatment in Australia had to face the possibility that this treatment would likely be unavailable to them if they were deported. This affected the treatment adherence of some participants. "They saved any treatment they had in case they were deported, carefully monitoring their clinical markers and balancing the treatment needs of the future against their state of health at the time."[18]

Case study of 'B', awaiting outcome of appeal. Not in detention

I am getting prepared ... While the doctors were telling me very carefully not to stop taking your medication at the prescribed times and in the prescribed amount ... I take half of the medication, of course with the risk of getting worse. But because I was having blood tests every four months and also I was, like, controlling my health condition, I saw that nothing like that was happening. So, in the end I have medication for a whole year.[19]

This issue is also relevant to those in detention, where it is reported health care providers have practices in place to prevent the hoarding of medication (for various purposes), although that was not the case as reported by 'A' above.

[18] Henrike Körner, at 12 above,.p.2
[19] Henrike Körner, at 12 above,.p.2

Recommendation 9: That guidelines including referral pathways be developed for the referral and treatment of HIV positive detainees so that they may quickly and effectively access expert HIV treatment from health care providers with experience in issues particular to those in immigration detention.

Managing Risk within Detention

Lastly, this submission notes that the risk of HIV transmission within detention centres remains an issue. It is our understanding that free condoms are made available in ways that limit affront to those with strong (cultural or otherwise informed) views about condom use and sexual practices. Without further specific information it is difficult to make comment other than we broadly welcome this practice as one component of a 'public health' management strategy. We would welcome the opportunity to have input, or for other expert service providers to be approached to review current practices aimed at limiting HIV transmission in detention.

Recommendation 10: That HIV prevention management be reviewed, drawing on expert advice from community based organisations and research institutions.