



“Consumer Issues in Australia & Asia”



Annie Madden

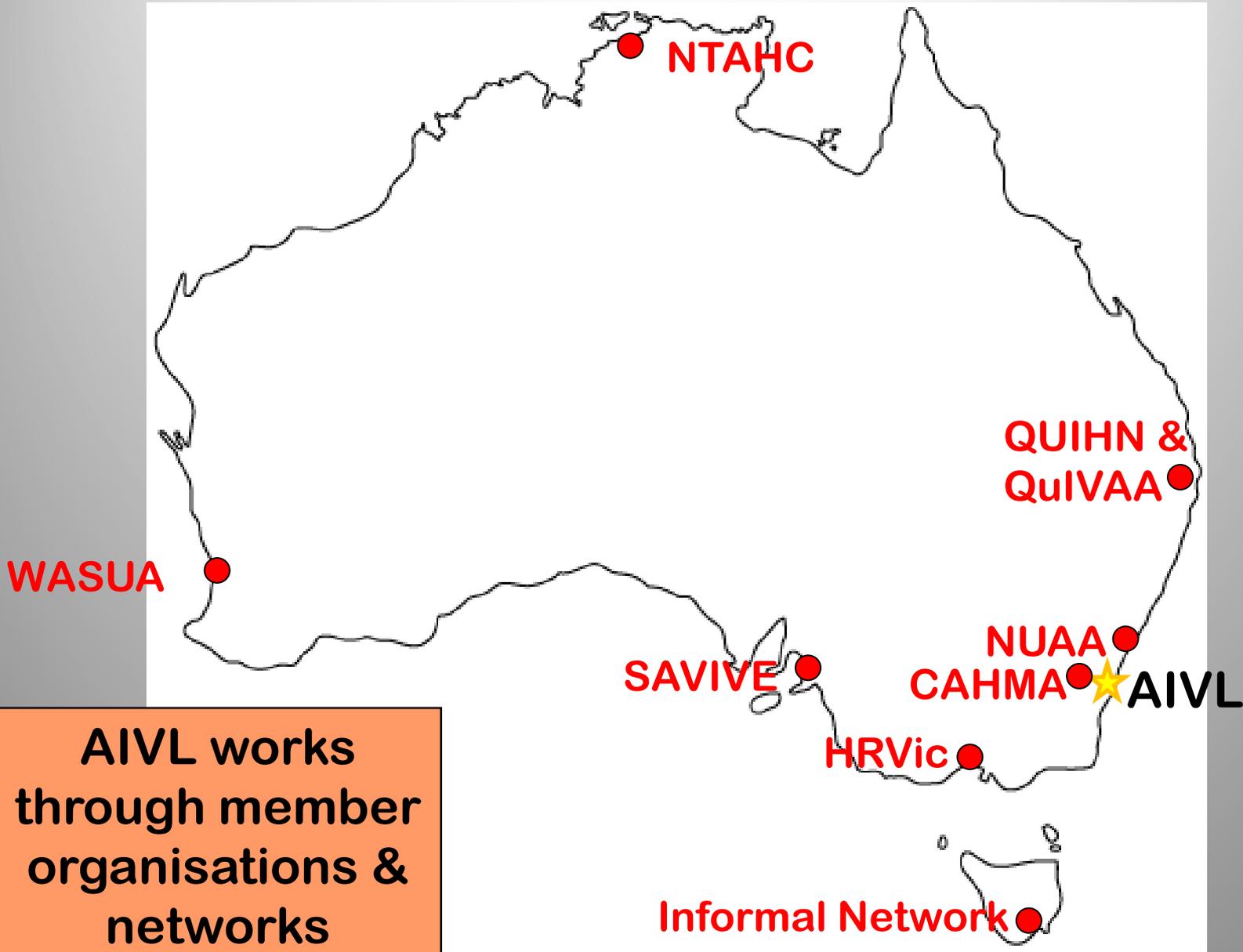
Executive Officer

Australian Injecting & Illicit Drug Users League (AIVL)



Overview

- **Overview of the AIVL National Network;**
- **Drug user organisations in Australia – some contemporary issues;**
- **Key issues for people who inject drugs in Australia;**
- **Drug user organisations in Asia – key issues;**
- **Key issues for people who use drugs in Asia.**



AIVL works through member organisations & networks

Overview - AIVL

- AIVL has been in existence for over 20 years;
- Grassroots organisation that developed out of local peer-based drug user organisations – demand for a national organisation;
- Commenced primarily in response to HIV – focus on IDU;
- Originally – Australian Intravenous League (AIVL);
- Spent first 10 years unfunded - hepatitis C funding allowed for organisational development (office/staff);
- 2002/3 changed name - retained focus on PWID;
- In 2012 AIVL still unfunded for illicit drugs/drug treatment work;
- AIVL National Network – highly regarded internationally/the model.

Issues for DUO in Australia

- **Myth: DUOs aren't "representative";**
 - No community-based organisations are 100% representative;
 - AIVL and its members are "peer-based";
 - We do not claimed to represent every individual PWID – we aim to effectively represent the issues needs of PWID;
 - Bring together consultation with PWID, available evidence & research and personal understanding/experience of drug use;
 - Properly supported, resourced and valued drug user representation can bring a unique perspective to the process.;
 - Can be a difficult role – critical, personal impact, isolating, etc.



Issues for Australian PWID

- **Lack of reliable/timely opioid related overdose data:**
 - AIVL has had a ‘gut-feeling’ that opioid related overdoses on the increase over past few years;
 - Changes to way cause of death data collected and reported at national level – 3 year absence of data;
 - But last reliable data 2008 – approx. 500 deaths attributable to opioid overdose (excl. non-fatal);
 - Recent work by NDARC estimates rates have continued to climb since that time with increase in deaths among older PWID;
 - Creeping back towards national road toll – need to act!

Issues for Australian PWID

- **Opioid Pharmacotherapy Programs:**
 - **Cost** - cost of accessing a community-based pharmacotherapy program is probably the No.1 issue;
 - One of the highest patient co-payments among all Australian health consumers – on average between \$50-\$85 per week;
 - All relates to dispensing fees – needs a federal govt solution.
 - **Access** - increasingly long waiting lists & access problems across the country – years in some areas/prison post-release;
 - Problems – ageing workforce, lack of interest from GPs/pharmacists – support & mediation services, cost (above).

Issues for Australian PWID

▪ Opioid Pharmacotherapy Programs:

- **Flexibility** – after cost, lack of flexibility/overly punitive nature of programs next major issue – greatly reduces attractiveness;
- Funding wasted on ineffective & humiliating urine testing – breaks down trust & therapeutic relationship;
- Lack of access to take-aways regardless of individual situation – interfering with employment & family commitments.
- **Options** – need more than methadone and bupe/naloxone;
- Greater range of oral opioids, injectables and pharmacotherapy support for dependent psychostimulant users.

Issues for Australian PWID

▪ **Naltrexone Implants:**

- Recent NSW Corner's Report highlights the extremely serious nature of this issue in Australia & urgent need for action;
- It is time these experimental devices are removed from availability under the TGA's Special Access Scheme;
- It is unprecedented for a device of this kind to have 'ongoing' SAS approval – partic when more effective & cheaper treatments are availability with full TGA registration;
- If it was any other group in society there would be public outcry;
- Continuing questions - efficacy, safety and ethical concerns.

Issues for Australian PWID

“Not one of the three deceased were entirely suitable for the (highly expensive) treatment recommended and administered to each by the Clinic. Each, though clearly motivated to find a solution to their various dependencies, had contra-indications to such treatment.”

“The medical and nursing staffing of the Clinic was extremely inadequate. Assessments, records and observations were cursory, and nursing staff were given almost no training and no supervision. It appears that a patient only had to present at the Clinic to be enthusiastically recommended for Rapid Opioid Detoxification no matter what their history or situation, without alternatives being discussed or considered or any information given on the risks involved.”

*** Sadly this is not the only Corner’s Report relating to deaths associated with naltrexone implants. There is also hospital adverse events data.**



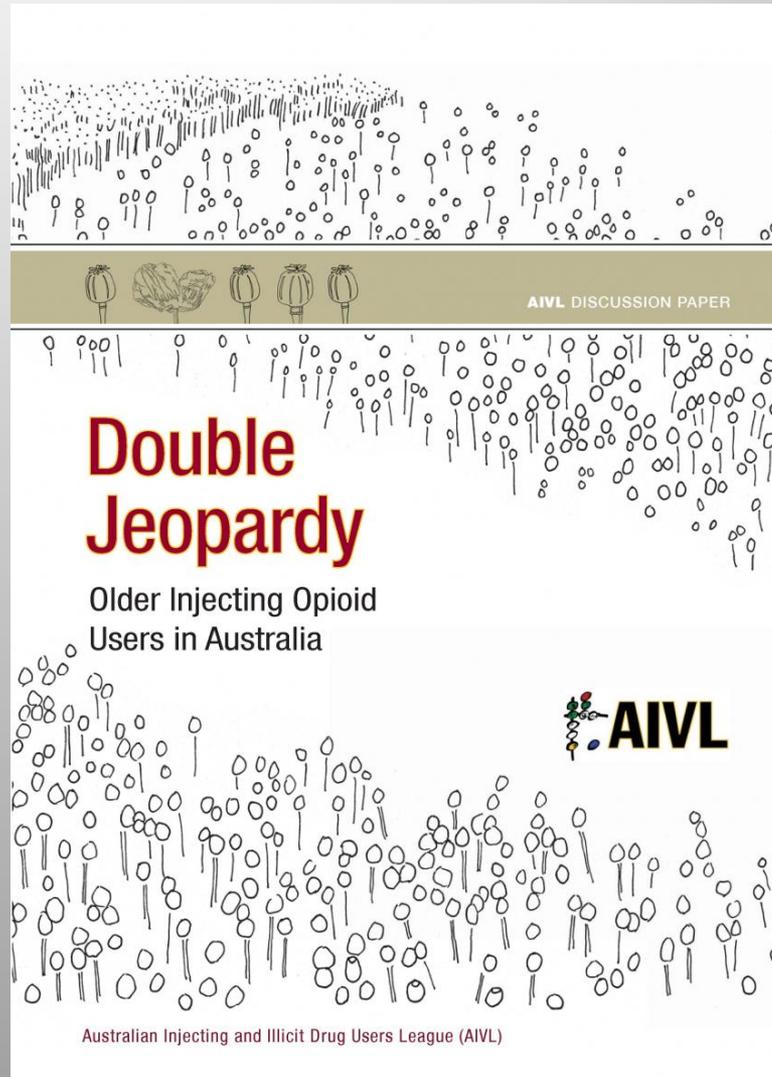
Issues for Australian PWID

▪ Ageing:

- We have an ageing cohort of opioid injectors in Australia;
- ANSP - Median age has increased from 27 years in 1997 to 37 years in 2010;
- Many people have surprisingly found themselves with an 'old-age' to live/manage – largely due to harm reduction;
- Many also coping with multiple complex and chronic conditions in addition to normal aging process incl. chronic hepatitis C;
- Anecdotally we know – fearful, lack of security, health & emotional impact of long-term criminalisation, ongoing stigma, very poor access to pain relief – need more research!

Issues for Australian PWID

“Double Jeopardy” Issues for Older Injecting Opioid Users in Australia – Oct 2012



Issues for Australian PWID

▪ Hepatitis C:

- Some progress on hep C incidence and prevalence – however numbers of new infections per year still unacceptably high;
- Major problem – extremely low numbers of people accessing treatment for chronic hepatitis C infection;
- Less than 2% of all people with chronic hepatitis C in Australia (mostly PWHIDU) have accessed treatment;
- Resulting in increasing levels of advanced liver disease complications and deaths from liver cancer (hep C now Australia's leading cause of liver transplantation, at least a doubling of current treatment levels needed to stabilise trend)

Issues for Australian PWID

“Auckland Statement on Viral Hepatitis 2012”

<http://www.aucklandstatement.com/the-auckland-statement>

- Almost 1300 signatures in less than a month;
- Aiming for 2000 signatures to support advocacy work;
- Ongoing advocacy campaign in relation to Federal Government & PBAC – access to 2 new treatment medications by Dec 2012;
- Need to address barriers to treatment for PWHIDU...



Issues for Australian PWID

AIVL National Anti-Discrimination Project :

- **Goals & Objectives:**

- Dispel myths and misconceptions about PWID;
- Reduce stigma and discrimination towards PWID; and
- Remove barriers and improve access to health services for PWID.

- **Target Groups:**

- General public/general community;
- Media;
- Health care professionals/health system; and
- People who inject drugs.

Research Phase

**Independent Market
Research Report –
Commissioned by
AIVL in 2009/10**

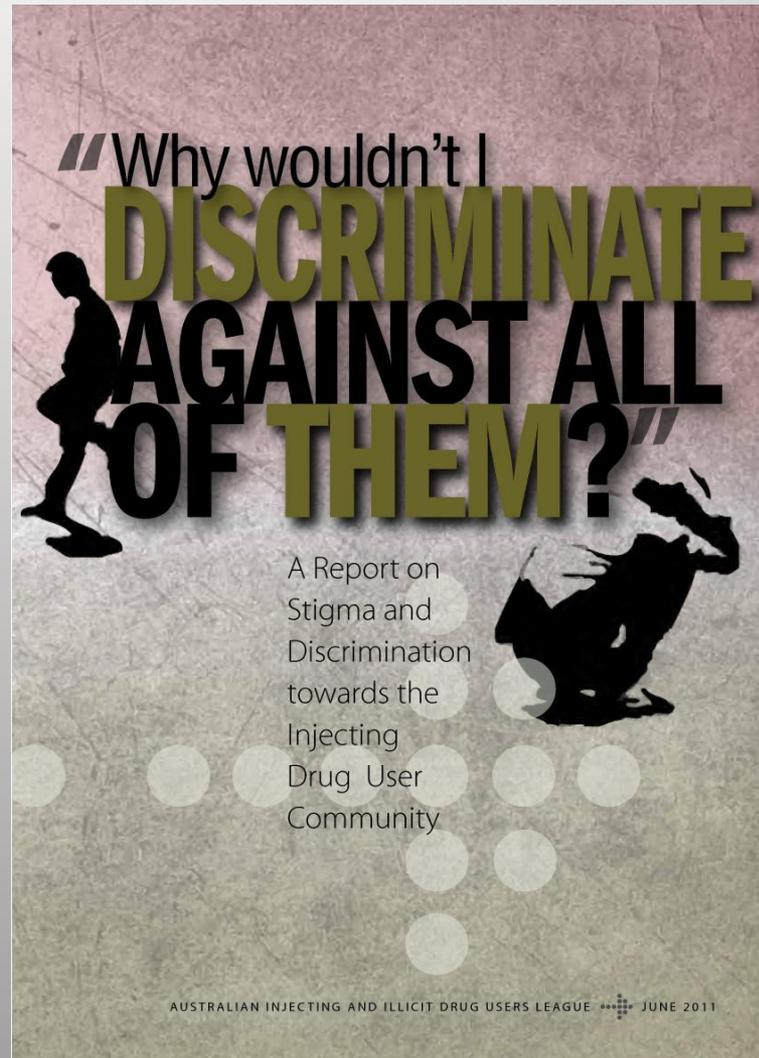


AIVL'S NATIONAL
ANTI-DISCRIMINATION PROJECT

MARKET RESEARCH REPORT 2010

Research Phase

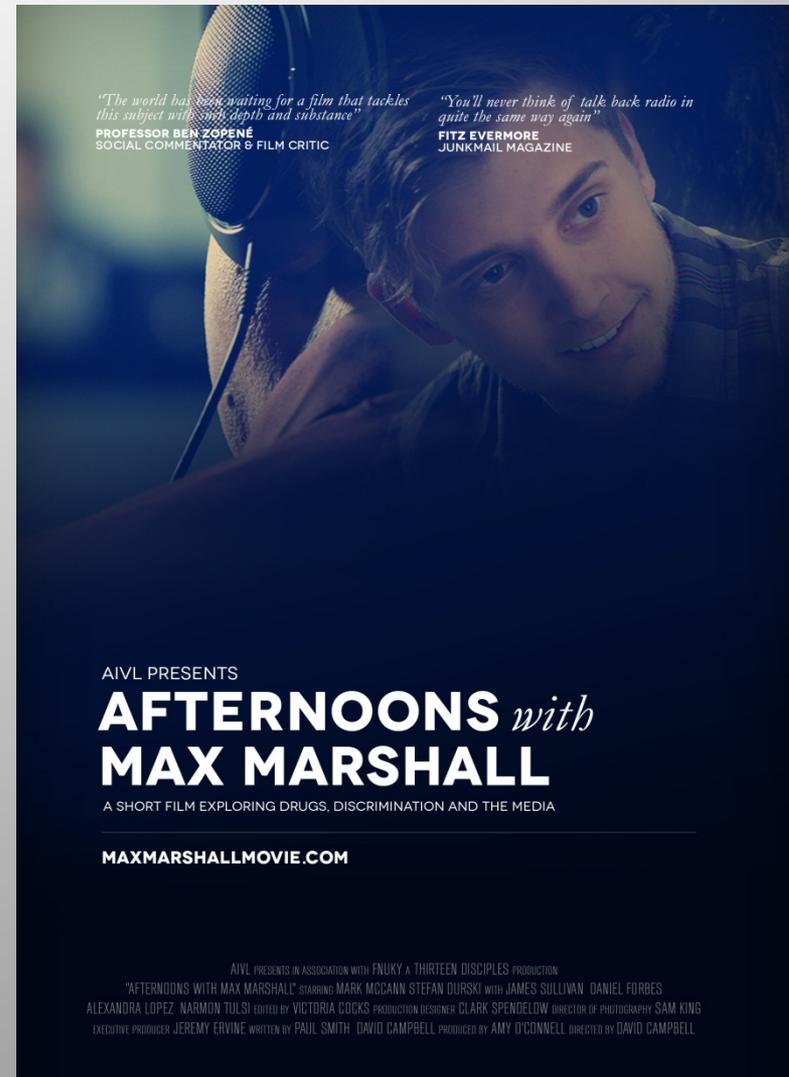
AIVL Report on Stigma & Discrimination



Project Phase

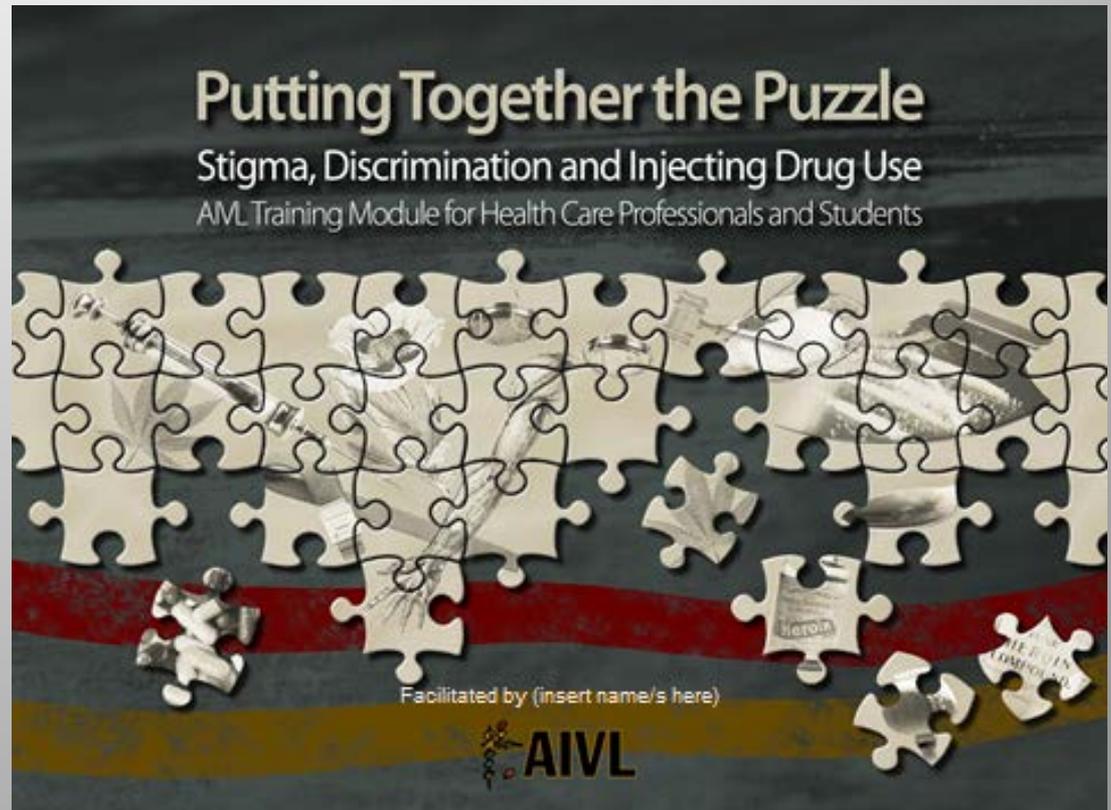
“Afternoons with Max Marshall”

AIVL’s first ever short film targeting the general public (post-secondary & tertiary students) and based on the media (talk-back radio): see at: <http://maxmarshallmovie.com/>



Project Phase

“Putting the Puzzle Together” – a national training module on stigma and discrimination targeting health care workers and students of medicine, nursing, pharmacy and dentistry



“Discrimination: Know Your Rights”

online resource and survey for people who inject drugs



The screenshot shows the AIVL website interface. At the top left is the AIVL logo, which includes a stylized figure and the acronym 'AIVL'. To the right of the logo is a navigation menu with buttons for HOME, GUESTBOOK, LINKS, and SEARCH. Below this is a secondary menu with buttons for ABOUT AIVL, BLOODY VIRUSES, SHOOTING UP SAFELY, SPEAKING OUT, GLOBAL ACTION, DRUG TREATMENT, and INDIGENOUS BUSINESS. On the left side of the page is a large illustration of a hand holding a syringe. The main content area is a white box with a distressed, torn-paper border. It contains the title 'Discrimination: Know Your Rights!' and a list of nine items, each preceded by a small circle icon. At the bottom of the page is a footer with links for CONTACT US, PRIVACY STATEMENT, CONDITIONS OF USE, and ©AIVL 2010.

AIVL

HOME GUESTBOOK LINKS SEARCH

ABOUT AIVL BLOODY VIRUSES SHOOTING UP SAFELY SPEAKING OUT GLOBAL ACTION DRUG TREATMENT INDIGENOUS BUSINESS

Discrimination: Know Your Rights!

- What Can You Use This Site for?
- What is Discrimination & Stigma?
- What are Human Rights?
- Quick Survey - Share Your Experiences of Discrimination
- Tips for Writing Complaints & Resolving Conflict
- Contact Your State & Territory Drug User Organisations
- How to Know if You Can Make a Complaint Under Law
- Places to Go to Make "Formal" Complaints
- Disclaimer

•CONTACT US• •PRIVACY STATEMENT• •CONDITIONS OF USE• •©AIVL 2010•

Issues for Asian DUO

- **AIVL International Program – “STANDUP”:**
 - AIVL receives funding through AusAID for a small program to support the development of DUOs in Asia (in 5th year);
 - Past 4 years – largely supporting development of Asian Network of People Who Use Drugs (ANPUD), Indonesian National Drug Users Network (PKNI) and provincial networks and Myanmar Drug Users Network;
 - Next 2 Years – will focus more on supporting the development of country level networks to build the voice of PUD in national strategies and policies & grassroots participation in ANPUD;
 - Indonesian National Drug Users Network (PKNI) and provincial networks;
 - Myanmar Drug Users Network;
 - Vietnamese Network of People Who Use Drugs (VNPUD);
 - HAARP & other donors and key stakeholders.

Issues for Asian DUO

- Biggest Issue for Asian DUO – not being supported to establish networks/organisations – so many countries do not have formal networks or they have to remain very underground;
- There are established and fledgling drug user networks in numerous countries including Indonesia, Myanmar, Vietnam, India, Nepal, Thailand, Malaysia – less so in China, Cambodia, Laos, Japan, Philippines, etc – but supporting small projects;
- Even where DUOs exist:
 - it is often very dangerous for the individuals concerned;
 - peer outreach workers routinely harassed & arrested by police;
 - they are rarely funded adequately or sometimes at all;
 - coping with high levels of HIV and hep C/poor treatment access among their members;
 - DUOs often not recognised for the contribution they can make;
 - Struggle to get a place at the table/actively ignored.



Issues for Asian PWUD

- Impact of criminalisation – drug laws/law enforcement initiatives have led to imprisonment & compulsory detention in both community and closed settings of large numbers of PUD;
- Numerous international reports have now documented the conditions and human rights abuses within such “treatment settings” and in detention centres including forced labour; humiliation, shackling, beatings and deaths;
- While some compulsory treatment centres are “community-based” many others are run by military and law enforcement agencies;
- PWUDs – may be identified as “patients” under formal policy responses but are frequently treated as “criminals” in practice;
- In some countries PUD must be ‘registered’ to get access to basic services incl. NSP;
- People are often locked up for years for minor offences or just for being/assumed to be a drug user without access to HIV treatment or other essential health services or basic human rights;

Issues for Asian PWUD

- In some settings high levels of police corruption also results in harm and serious human rights violations for individual drug users partic. female drug users;
- Funding can be provided to establish critical harm reduction programs such as NSP, OST, HIV treatment access only for funding to be withdrawn due to being 'time limited', only for a 'pilot' project or getting caught up in the domestic political agendas of donor countries – this obviously leaves the people who need those services in a highly vulnerable position;
- Without funding support through international donors and Global Fund, and the work of peer-based and civil society organisations the response to issues such as HIV would be non-existent in some countries;
- Despite millions of PWID, extremely high rates of HIV & HCV many countries still have little or no access to NSP, OST, etc.
- High levels of HIV/HCV co-infection – driving agenda for affordable HCV treatment access.



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