





THE HISTORY OF DRUG USER ACTIVISM IN AUSTRALIA

Two decades of experience have demonstrated, with a high degree of certainty, the effectiveness of our early response to HIV (and other infectious agents) among PWIDs. Equally certain are the essential elements of our successful response including harm reduction, peer-based education and services - and properly resourced drug user organisations. The experience of other nations shows that, in the absence of this comprehensive approach, HIV epidemics can develop rapidly among PWIDs.

To date, Australia has succeeded in preventing a major HIV epidemic among injecting drug users, but the price of success is eternal vigilance, and the maintenance of political support requires constant reinforcement.

If there is a unique feature of the Australian HIV response, it is the strength and resilience of the Australian drug users' movement. However, maintaining a successful response beyond 2014 rests upon the government's willingness to support our organisations into the future - a future that, if current indications are anything to go by, is anything but certain.

Despite our long history and many important achievements, we continue (as do our peers in all corners of the world) to struggle against an overwhelming conspiracy of silence - silence that causes people to remain marginalised, and which utterly prevents the broaching of subjects like pleasure and the positive and life affirming experiences that can be associated with the use of drugs. It is a silence that erodes our hopes for an end to prohibition, the removal of criminalisation, and the elimination of that relentless discrimination

and stigmatisation which plagues the daily lives of PWIDs in contemporary Australia.

The history of drug user organisations in Australia is rightly a proud one - and must continue into the future. Whether we get to write the next chapter will largely depend on how much we are valued, and therefore supported, by governments, funding bodies, the general community and, of course, by our own drug using community - not just in good times, but in challenging ones as well. This is the true measure of support for our role and will be the key factor in whether we not only survive, but thrive into the future.

Being asked to write this article was an absolute privilege. The points in time, the reflections I have made are entirely personal. I could have selected many other examples of the positive changes we have made to the lives of not only drug users but their partners, friends and families, and, indeed, the community at large. If others among my peers in this monumental struggle were writing this piece, they may well have chosen to underscore other aspects of our history. I guess that is the point really; we are a highly diverse lot, united under a single banner.

Our individual experiences are ours alone, but there is one very important thing we all share: the will to improve the health and human rights of people who inject and use illicit drugs - both in Australia and as part of a growing global movement for change.

Together we are building a future for people who use drugs that does not involve the routine violation of our right to be treated with dignity and respect.

Annie Madden 2014

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A HISTORY OF DRUG USER ACTIVISM IN AUSTRALIA THROUGH THE EYES OF AIVL'S ANNIE MADDEN

By any measure, Australia's long history of drug user activism is a proud one.

Despite the illicit nature of drug use and the ongoing criminalisation of users, drug user activism has contributed a compassionate and challenging voice to the public debate about drugs for nearly three decades. There are few countries in the world that can boast such a strong and vibrant network of advocacy bodies - fuelled, of course, by the energy of countless passionate individuals.

So, what is it that sets Australia apart? What makes our brand of activism and our organisations unique? How do we explain our refusal to fold in the face of systemic discrimination and stigmatisation, and the relentless War on Drugs that is, in essence, a war on people who happen to use drugs?

As someone who has been on the frontline of the struggle for most of its history, I have seen too many outstanding activists die before their time - be it from AIDS, overdose, the arbitrary violence of criminalisation, and now, increasingly, from hepatitis C and other (largely preventable) health problems associated with long term injecting drug use.

But I have also witnessed remarkable people standing tall for what they believe in, and the tremendous power of committed people working together to demand the right to be treated with dignity, respect, and in accordance with their basic human rights.

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In the beginning was the word, as the good book says, and the word was HIV. Okay, it's not a word as such, more of an acronym, but you get the picture....!

Even before the looming spectre of HIV/AIDS appeared in the mid-1980s, there were localised groups of drug users meeting and organising in Australia. Generally, these groups were associated with methadone clinics (particularly in NSW) and their focus was on improving access to methadone, and supporting those seeking to move away from injecting drug use. However, with the emergence of HIV, the nature of these early groups was to change radically.

Other groups and networks were also forming with specific political and advocacy agendas, particularly those highlighting the need for drug law reform. Indeed, it was a group of drug users in Victoria who first formed with a more political, reformist agenda - even before the birth of VIVAIDS (now Harm Reduction Victoria) - NUAA in NSW heralded the contemporary era of Australian drug user organisations.

But these early groups, regardless of their purpose or what brought them together, were isolated. Nothing in the scant records that remain of that era suggests that they ever connected or communicated with each other.

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With the dawn of the 1980s, Australia's injecting drug user community became increasingly aware of the unfolding threat posed by HIV. Although we had limited access to information about the spread of the virus

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among our peers overseas, we had no doubt of the need to mobilise and take action.

Early activists faced an enormous uphill struggle against entrenched prejudice and harmful stereotypes. The very notion that injecting drug users might care about their health or that they could be educated about safer drug use was considered bizarre. Accepted wisdom held that, as a group, we would be unlikely to respond to HIV prevention efforts – but, as drug users ourselves, we knew differently. We knew their assumptions were wrong. We knew that the drug using community would share important information, and that we would be prepared to educate ourselves and each other and to look out for each other.

We had privileged access to a highly marginalised community, forced underground by the law and deprived of services and support. We knew we could use this access to drug user networks to supply both clean injecting equipment and essential HIV prevention information to people when they needed it most – when they were scoring and using together.

For their part, governments remained cautious. Ultimately, they were wary of appearing to condone injecting drug use. However, they were pragmatic enough to accept that a reorientation of public health policy towards harm reduction and a partnership with the drug using community were necessary to avoid an HIV epidemic in Australia.

This realisation paved the way for a national roll-out of needle and syringe programs

(NSPs) and funding for HIV peer education. Drug user organisations were quick to advocate for such policies and programs, and spearheaded the engagement of affected communities, the provision of peer education and the supply of sterile injecting equipment.

The rest, as they say, is history. Ultimately, it was the actions of drug users which prevented a major HIV epidemic in Australia, and, to this day, we maintain one of the lowest rates of HIV among injecting drug users in the world.

Despite governments' misguided preconceptions regarding users' careless attitudes towards their own wellbeing, by 1990 peer-driven drug user organisations had been established in every state and territory of Australia. It was a massive achievement which has never been sufficiently recognised. Surely it is of some note that members of an extremely marginalised and maligned sector of society came together, stood proud and announced to the general community *'we are people just like you, we have a right to dignity and respect, we have a right to health and to services that meet our needs'*.

Drug user organisations have always had to fight hard for their existence. Then, as now, it is no easy task to maintain the flow of funding (even small amounts of funding) required to provide education and services for users, and to advocate for issues which intimately affect drug users' lives.

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But a little bit about myself...

When HIV first emerged in Australia, I was living in Queensland and injecting drugs...as often as I could. That's the truth of the matter. For reasons we all know, people who inject or have injected drugs tend not to express their real feelings about drug use. We are forced, over time, to perceive our experiences as entirely negative. But, let's think about it for a minute... Why would anyone continue to inject drugs if they got nothing positive, nothing genuinely enjoyable, from the experience?

shifted from the Health Department into the Office of Prime Minister and Cabinet.

The Australian National Council on Drugs (ANCD) was established, and its first chairperson was a blimpish and abstemious Salvation Army Major. This independent advisory body reported directly to the Prime Minister and was complicit in the coining of the subsequent 'Tough on Drugs' agenda. What's more, the government officially redefined the term 'harm minimisation'. No longer was it to be interchangeable with 'harm reduction'. Instead, it became an umbrella term for a new three-pronged approach to drug policy: a) supply reduction (law enforcement, courts, prisons, etc.), b) demand reduction (drug prevention, drug treatment, etc.) and c) harm reduction (NSPs, drug user organisations, peer education, OST, supervised injecting rooms, etc.).

It was sold as a 'balanced' approach and, to this day, 'harm minimisation' remains at the core of Australian Government drug policy.

But make no mistake, this new framework did not (and does not) include a guarantee that the three 'domains' be addressed evenly - or with any kind of 'balance'. Indeed, recent research confirms that, of the \$1.7 billion spent in 2009/2010 on illicit drug use, only 2% was spent on harm reduction, compared with 65% on supply reduction.

This same research also reveals an almost 50% reduction in the Government's investment in harm reduction since 2002/2003. Notably, in this report, OST is listed under the demand reduction (rather than harm reduction) domain. Almost exclusively, harm reduction equates to investment in NSPs (and the minuscule amount put aside for Australia's sole supervised injecting facility in Sydney).

Thankfully, despite these major shifts in the drug policy environment during the Howard era, our drug user organisations managed to retain their funding. It may sound like a low bar, but survival under these adverse

circumstances was a significant feat in itself, particularly for such politically vulnerable groups. But, given the importance of our mission, mere survival is not sufficient.

Furthermore, this ongoing struggle to survive reflects negatively on how we view our organisations and how they are viewed from outside. Perhaps most importantly, an organisation struggling to survive is hobbled in its efforts to assume a leadership role and effect social, political and legal reform. It would be grossly unfair and simply incorrect to characterise the achievements of drug user organisations during this challenging time as

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nothing more than self-interested survival.

Nevertheless, the continued existence of drug user organisations remains a major objective in itself. Not because survival per se is our goal, but because we can at least maintain a consultative framework to effectively represent Australia's PWIDs.

We did, of course, do much more than subsist under the "Tough on Drugs" regime, providing peer-based services and conducting innumerable campaigns and projects for our community. We contributed to important wins for PWIDs in the advocacy space - not least of which was a successful challenge to the Howard Government's attempt to erode legal protections for drug users by effectively legalising discrimination against people 'assumed' to be illicit drug users or 'drug addicts'. Such a change would have effectively given a green light to poor treatment and human rights abuse. That we were able to lead a broad coalition of organisations and individuals to victory in this case remains, to my mind, one of our most important attainments during this time.



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suits: providing the highest attainable standard of health in prisons by implementing NSPs is but one case in point.

Work on the design and implementation of this world-leading heroin prescription trial was extraordinary by all those involved – not least the key researchers at the Australian National University. An enormous amount of work was also performed by the under-resourced, local drug user organisation (ACT IV League).

As we are now well aware, if such trials are to attract and retain heroin users, an officious, highly restrictive structure is not ideal. Even so, everything seemed to be heading in the right direction. To our surprise, the proposal for the first phase of the trial was approved in 1996/7 by the Ministerial Committee on Drug Strategy (MCDS). This committee (which, interestingly, no longer exists) was made up of Health and Police Ministers from every state and territory of Australia. Subsequently, the Federal Health Minister, Michael Wooldridge, advised that the first phase of the trial was to proceed.

There were celebrations of course, but regrettably, they were short lived. Prime Minister John Howard directly – and, it needs to be said, in an unprecedented manner – intervened and overturned the decision of the MCDS. With the stroke of a pen, the ACT Heroin Prescription Trial was dead.

This forward-looking and desperately needed harm reduction initiative was over before it began. Years of work went down the drain overnight. It is no exaggeration to say that the hopes and aspirations of hundreds of thousands of injecting drug users in Australia were crushed that day in 1997.

Over the past seven or so years, data has again shown marked increases in opioid related overdoses, but, to date, and despite the ongoing need, Australia has still not conducted a heroin prescription trial.

Drug user organisations immediately protested the government's decision to halt the trial. Our resistance, though ultimately futile, revealed a powerful determination that at times was labelled intimidating. We do not apologise for this – to our mind, the fact that drug user activism can demonstrate such palpable strength is an absolute positive.

Yet the decision was, without doubt, a crushing blow – not only to the lives of past and future PWID, but to the ongoing development of harm reduction policy and the continued support for drug user organisations in Australia.

Certainly, at the international level, the government's long-term investment in NSPs and our comparatively high level of accessibility to opioid substitution programs (OSTs) is regarded as evidence of Australia's ongoing commitment to the harm reduction model. Similarly, the fact that we actually have funded drug user organisations at the state and national level, unlike many other countries, is also applauded.

And, believe me, no one is more proud of the strength and survival of the national network of drug user organisations for over 25 years in Australia. But, should we really be content to measure our commitment against countries where there is little or none of the above? As a prosperous Western country, should we not be asking why we have not done more, why we have not done better, when we have the means at our disposal to do so?

The Howard Government held power from 1996 to 2007. With it came, not only the torpedoing of the heroin trial, but a seismic and very public shift in Australia's drug strategy. As a policy item, illicit drugs were

Of course injecting drugs is enjoyable, but, due to its illegality – particularly for regular or dependent users – it comes with unavoidable negatives: social isolation, the need for secrecy and, of course, stigma.

As a young drug user activist, together with my many peers across the country, I was committed to alerting governments to what might happen if they did nothing about HIV, and then convincing them (somehow) of the absolute need to give injecting drug users free injecting equipment – so they could continue to inject the very drugs which governments opposed!

At that time in Queensland, injecting equipment was only accessible with a doctor's prescription – and only then if you were a diabetic. Today, with NSPs operating all over Australia, it seems almost inconceivable that free access to equipment was non-existent. Acquiring syringes was such a struggle that sharing and reusing them was simply part of using culture. And, as a young injector, I just slotted in.

There were one or two 'good' pharmacists who would provide fits without too many questions, if you were lucky enough to have a prescription. Sometimes 'by accident' they would leave a box of fits at the back of the pharmacy for us to access after-hours. But, for the most part – as it remains today in many countries across Asia and Eastern Europe – sterile fits were a bitch to get hold of.

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With the 1990s, Australia got down to the business of developing a national response to HIV. It was an important time for harm reduction, with significant investment in both the growing national network of NSPs (including peer-run services) and large-scale expansion of the methadone program. It was also about this time that hepatitis C (HCV) was first identified as a distinct form of viral hepatitis. Sadly, we began to understand that, while we had acted in time to prevent an

HIV epidemic among users, the same could not be said for HCV. Newly available tests – often part of routine screening in methadone clinics – revealed increasing numbers of people already infected with HCV.

Within a few years, the true extent of the HCV epidemic began to unfold. The infection rate among injecting drug users was disturbingly high and the rate of new infections showed no sign of abating. Despite these dire signs, drug user organisations struggled to gain political



traction – and therefore funding – to support the urgent need for expanded services that would address HCV as well as HIV. Indeed, we found ourselves dealing with a scenario entirely different from what we had experienced with HIV. Australian drug user organisations have always understood why we receive government funding. It is not out of care and concern for us or commitment to what we represent, or seek to achieve, as self-advocates for the health and human rights of drug users. No, governments fund us out of fear that we will serve as conduits of HIV into the general community – the people they actually care about.

Over the many years I have worked in drug user organisations, I have frequently been



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challenged about the statement above. These challenges often come from others in the harm reduction sector and even from drug law reform advocates. Interestingly, some take exception to my characterisation of governments as anything other than wholly genuine and compassionate when it comes to their HIV response. However, these sorts of sentiments were expressed outright on several occasions to early drug user activists (including myself) by both parliamentarians and government officials of the day.

Granted, it is a harsh truth to accept from one's own government and from a country that so prides itself on its swift response to HIV; but given the prevailing discourse (both then and now) on drugs and drug users as agents of social evil, it is plainly more likely that the government would act to prevent HIV infection penetrating the general community than they would to protect the health of people who inject drugs (PWID). Appreciating this important aspect of the history of drug user organisations in Australia is critical to understanding why our survival remains tenuous to this day.

It is also an important clue as to why it took until 1997 for drug user organisations to receive funding to prioritise HCV education and services among PWID. Unlike HIV, HCV is not classified as sexually transmissible and therefore does not present the same kind of threat to the wider community as HIV. HCV is largely a problem among those who inject or have injected illicit drugs. In Australia, approximately 80 percent of the 230,000 people with chronic HCV infection have contracted it via unsafe injecting practices and over 90 per cent of all new infections occur

within the PWID community.

It is not difficult, then, to see why governments were slow to prioritise a disease which generally limited itself to 'drug fiends'. What's more, it did not seem likely to burden the health system, as, in the short term at least, those infected did not become seriously ill. It remains an irony of the Australian drug user movement that funding for a national HCV response (in 1997) also saw the first provision of secure and substantive operational funding for a national drug user organisation.

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The Australian Intravenous (IV) League (or AIVL, as it still known) had been formally established in 1992, and its emergence from an increasingly well-established network of peer-based state and territory organisations (rather than vice versa) is proof of the grassroots nature of drug user activism in Australia.

Once local drug user organisations began to receive funding to counter the perils of HIV, it became apparent that a peak body was needed to act as a collective voice, to inform politicians and society at large of significant, national issues for PWID – issues beyond the depredations of blood-borne viruses, but of no less importance.

For the first decade of its history, AIVL had subsisted as an unfunded, voluntary, almost virtual organisation. It was one thing for governments to fund local groups to provide HIV prevention programs but it was an entirely different proposition to formally acknowledge a national peak body with a clear advocacy agenda on the broader topics of health, law and human rights for PWID.

It was in this context that hepatitis C supplied an unexpected opportunity. Its emergence shone a light on the previous success of Australia's harm reduction approach to HIV, one which hinged on the organic involvement of the affected community. This begged the question: could not this same policy be applied with HCV?

During the 90s in Australia, heroin became cheaper and more readily available. Inevitably this led to an unprecedented escalation in overdose deaths. Many of us in the drug user movement were already managing the trauma and grief caused by AIDS casualties – now our community had to come to terms, silently in many cases, with the relentless nature of

As the 1990s wore on, overdose numbers continued to climb – until they reached and surpassed the national road toll (over 1000 per annum at the time.) In mainstream Australia - and in the recently elected, highly conservative government led by Prime Minister John Howard – the panic set in.

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death from heroin overdose in a criminalised environment.

To be clear, I say 'silently', not because those who suffered had no wish to cry their loss to the world, but because they could not do so without exposing themselves to potential legal repercussions. What's more, importantly, we simply didn't think that the broader community would care.

Sound like an overly harsh indictment on society? Well, perhaps... but though it may seem a pejorative assessment of the general public's attitudes, the fact remains that people experiencing the loss of family and friends from fatal overdose could not express their grief openly, due to moral and legal objections to people injecting heroin in the first place.

The ACT Heroin Trial was one of the proposed responses to this crisis. It was to be an experiment with prescription heroin in the Australian Capital Territory, right next to the beating heart of the federal government. These were uncharted waters, to be sure. Despite its harm reduction credentials to this point, it was hard to believe that Australia might challenge the stranglehold of the UN Single Convention and the complete and utter outlawing of heroin (aside from the legal opium poppy industry in the state of Tasmania).

Under the UN Single Convention, the trial could only be allowed if it was for medical or scientific purposes – and, as a clinical trial, it met this requirement. It has always struck me that the Australian Government was so willing to abide by the letter of the Single Convention on this point, but it routinely flouts its obligations under international law when it

