

Private Lives, Public Policy

Presented at the International AIDS Conference in Barcelona, Spain July 2002.

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1. Introduction:

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My name is Annie Madden and I am the Executive Officer of the Australian Injecting & Illicit Drug Users League known as "AIVL" for short and I will refer to the organisation as "AIVL" for the remainder of this paper...AIVL is the national injecting & illicit drug users organisation in Australia and it is also the peak body for the local or regional drug users organisations across Australia. It is important to state from the outset that AIVL and its member organisations are run by and for active injecting drug users. I would like to begin my presentation this afternoon with some personal background information because I think that it is important both in the context of this conference and in relation to the theme of this session – private lives/public policy...

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I would like to begin by telling you that I am a current or "active" injecting drug user. I have been a heroin injector for over fifteen years. I am currently on the methadone program in Australia. This is the second time that I have been on the methadone program, and this time I have been on the methadone program for the past eight years. I don't always identify as an active injecting drug user at international conferences such as this. The main reason for this is that it is a very hard thing to do. It is dangerous for me to openly identify as an active injecting drug user when I am in another country and of course I also risk being judged by others attending the conference. **Slide 4** The reason I decided to take these risks however, is because of the general lack of active injecting drug users represented at this conference.

I may be wrong but as far as I know, I am the only 'out' injecting drug user at this entire conference. Think about it... an international conference on HIV/AIDS with over 15,000 people in attendance and I may be the only active injecting drug user speaking at or attending the conference. I believe that this state of affairs says a great deal about where injecting drug users are situated when it comes to HIV/AIDS. **Slide 5** Where are the many thousands of active injecting drug users affected by HIV from around the world – why aren't they at this conference?

When I began to think about this question, it occurred to me that the main reason why drug users are so under-represented at this conference can be linked directly to the very issue that we are discussing in this session this afternoon, that is, POLICY. **Slide 6** What I mean by this is that it is policy that keeps active drug users from participating in conferences like this one and many other forums and activities in society. It is policy at the organisational level that prevents active drug users from being employed as staff and therefore being funded to attend these conferences. It is policy at the local or

regional government level that prevents access to methadone programs or at least flexible methadone programs that allow active drug users to travel and attend international conferences. And it is policy at the national or country level that prevents people with criminal records being able to get visas and enter other countries for the purposes of attending conferences like this one.

And these are just a few examples of how public policy affects the private lives of injecting drug users in one specific area – there are many more areas and many of these other areas of public policy affect the lives of drug users in far more serious ways. To further illustrate the impact of public policy on injecting drug users and to look at the importance of active drug users being supported to undertake work in the policy and advocacy area, I would like to use the remainder of this presentation to look at two specific areas:

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1. I would like to take you through the National IDU Policy Program that we run at AIVL to highlight just how important it is for drug users undertake their own policy lobbying and advocacy work and what can be achieved if this work is funded and supported adequately and;
2. I would like to finish up this presentation with some more general thoughts and comments about IDU, policy change and the future...

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2. The Missing Link...

Before I begin talking about the AIVL Policy Program, I would like to stress that I do not see myself as any kind of expert. I don't profess to know about the experiences of all injecting drug users in all parts of the world, I am just a drug user with a particular set of experiences in the Australian context and some information that I believe is important to share with others. I am not holding the AIVL Policy Program up as a model that can be directly transferred into other cultural, social, economic or political contexts, but I am hoping that our experiences in Australia will inspire you to think about how you are working with and supporting local drug users in your country to be involved in the policy process and have a voice on the issues that affect them in whatever way works for them.

One thing that always strikes me when I attend conferences both at home and overseas is the lack of discussion about the importance of involving active drug users in public policy. It seems to me that we only ever talk about the importance of IDU peer education, drug users educating each other about safer injecting practices and HIV prevention but never or rarely about the need for IDU to be supported to engage in social action - policy lobbying and advocacy work to fundamentally change their lives rather than educating each other to simply survive under existing policy structures. **Slide 9** From where I stand as an active drug user, I see peer education as a way for drug users to survive the status quo and policy lobbying and advocacy work as a way to transform the status quo so that drug users can have a chance at a real life not just mere survival. To highlight the differences in terms of practice between peer education done by drug users and policy and advocacy work done by drug users I would like to briefly take you through the main aspects of the AIVL IDU Policy Program...

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3. AIVL Policy Program:

The AIVL Policy Program has been funded for two years and is funded by the Australian Federal Government. This is a significant point because not only does funding make it possible for us to work and organise in a way that would not be possible without funding, it is also the only funded national IDU run policy program that I am aware of in the world. The reason for this is that governments are not usually very keen to fund NGOs to criticise their policies and lobbying against them. For this reason most drug user organisations, if they exist and get funding at all, only get funding to carry out peer education programs and activities. The AIVL Policy Program is certainly unique but it should be stressed that it is not that the Australian Government is any more interested in funding groups to criticise them, it is just that after years of unfunded lobbying and policy activity on behalf of AIVL we were eventually able to convince the HIV and Hepatitis C Section of the Commonwealth Health Department that funding us to be at the policy table was not as threatening as they may have believed it to be.

Over time we managed to demonstrate to them that there were benefits to both the government and therefore the broader community to consulting directly with drug users. **Slide 11** They would have access to information that they wouldn't otherwise have had access to and there was always the very attractive notion for a government of having a degree of control over us – if they are funding us to undertake certain legitimate activities, then we would, theoretically, have less time to undertake activities that they didn't approve of... In short I suppose what I am saying is that it has been a process of compromise. **Slide 12** We have traded off certain things to get some resources, a space to work from and some paid staff so that we can have more of a profile, operate more consistently, support more active drug users to be directly involved in the organisation because they have paid employment and have a direct say in government policy. The government on the other hand, has taken the risk of legitimising drug use and drug users in order to gain access to information and a degree of on the ground intelligence (although we only ever tell them what we want them to know) so that they can develop more effective policies and ultimately, stay in government.

To show you what I mean I want to quickly look at just a few of the policy and advocacy activities that we are doing as part of the AIVL Policy Program...

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- **Research Collaboration** – participating in national IDU research projects, commissioning peer-based research (give example of safe disposal research), developed a set of national ethical guidelines for research involving IDUs (explain ANCAHRD/NHMRC endorsement process), acting a chief and associate investigators on major research projects.
- **Representation** - representing IDU at conferences, national forums, workshops;

- **Policy Advice** - providing policy advice to government, service providers and other stakeholders on health issues affecting IDU particularly in relation to HIV/AIDS, hepatitis C & B, harm reduction, drug treatment, primary health services, etc;
- **Capacity Building** - for peer educators and drug user advocates (refer to the development of the Certified Competency Based Training Program in Drug User Organising covers history of DUO, policy development and advocacy skills, working with the media, communication skills, resource development, peer education, basic administration – a basic course in drug user organizing – hope to upgrade it to a diploma in DUO over the next few years. One of the major aims of the course is sustainability of the Australian Drug Users Movement - to bring new drug user activists into the local drug user organisations and AIVL. We have fully funded positions and the course is designed specifically to be completed by active drug users so there is lots of flexibility in how it is done and the level of the course material.
- **Supporting Member Organisations** - assistance, support and capacity building for AIVL member organisations to ensure a strong national network and on the ground response;
- **Service Provider Training** - education and training for healthcare professionals in relation to issues affecting IDU;
- **Advocacy** - representing the 'voice' of current IDU on government advisory structures we are currently represented on the major national committees providing policy advice to the Federal Health Minister on HIV/AIDS and hepatitis;
- **Media Campaigns** - promoting the health needs of IDU through media work (media releases, media interviews, write articles for publications, participate in IDU radio shows);
- **IDU Policy Statements** – we develop national policy position statements on key issues that affect IDU such as NSP, HIV/AIDS, hepatitis C, Access to Drug Treatment, Harm Reduction, etc;
- **National Policy Magazine** – we publish a national IDU policy magazine called “Junkmail” which is designed to encourage drug users to get more active on the policy issues that affect them and use the magazine as a way to get their opinions and perspectives out into the broader community. The magazine is very popular we print 5000 copies every edition, have printed 3 editions so far, it is already considered a collectors item amongst drug users who read it from over to cover and every edition we get more and more letters, articles on policy issues from ordinary drug users. It is a major way that the drug user representatives can get information out to drug users on the street and in their homes about what governments and services are doing on a policy level. Junkmail is a very good example of the difference between policy and peer education activities – drug users are so happy to be getting something with analysis and issues rather than just being targeted with safer injecting and harm reduction information all the time. Drug users are whole people with many interests and they want to know more than just how to inject safely.

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How soon is now?

To conclude I would like to talk a little about the future in relation to IDU and public policy in Australia and beyond. I have spent a good deal of this presentation talking to you about the policy work that we are trying to do at the local and national level in Australia, but the truth is that this is extremely hard work with few if any clear victories - and the main reason for this is the current policies and laws in relation to illicit drugs in almost every country in the world.

While AIVL has been funded to conduct a National Policy Program, the major policy area of drug law reform is going nowhere except backwards. **Slide 15** Australia has harsh criminal penalties in relation to illicit drug use, prisons that are full to overflowing, court diversion programs that are mostly focussed on cannabis offenders, chronic shortages of drug treatment places, legal barriers to the effective operation of NSPs including self-administration offences that keep drug users away from NSPs due to fear of arrest or police harassment and laws that make it a criminal offence for a drug user to give another drug user a clean fit and there is no access to new injecting equipment in prisons despite high level of injecting in Australian prisons.

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Despite overwhelming evidence of their effectiveness in other countries, Australia is still dragging its heels and fighting over whether to implement safe injecting rooms beyond the single, ridiculously expensive Sydney trial and we have a Prime Minister who has unilaterally decided (with a little help from the US authorities) and despite a good deal of community support that Australia will not have heroin prescription trials any time soon. And I haven't even mentioned the endemic police corruption, the routine violation of the human rights of drug users and the continual undermining of any reasonable debate on the need to legalise and properly regulate current illicit substances.

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While this could be the story for any number of countries, the fact is that this type of political intransigence on key public policy issues is one of the single biggest reasons why we have a HIV epidemic amongst IDU at all! It is the reason for many of the problems that I have outlined above and, as I began, it is also the reason why I am the only person standing here saying these things to you at this conference. The current drug laws create a wall of silence around any reasonable debate and real solutions to these issues. The current drug policy debate in Australia and most other countries is a self-fulfilling prophecy – it states on the one hand that drugs are bad and must be controlled through legal sanctions but it is these very legal sanctions that create the majority of problems associated with illicit drugs. As long as these substances are illegal, there will be an inseparable connection between illicit drugs and health and social problems such as HIV, hepatitis, poverty, discrimination, overdose, etc. For the average person on the street it appears that it is the drugs themselves, not their illegality that make them so

problematic – and politicians do very little to discourage this thinking because it means admitting the total failure of their very expensive policies and a complete restructuring of the world as we know it.

But their policies have been a complete and total failure and despite what politicians say, there is no hard evidence to suggest that the world would be a far worse place if we were to rethink our current approach to illicit drugs, in fact I would say that there is evidence to the contrary. While it is a whole different presentation on its own to explore the pros and cons of drug law reform in more detail, suffice to say that it is a debate that we **MUST** have if we truly wish to address the enormous health and social problems currently associated with illicit drugs including HIV/AIDS.

I was thinking about the protests that have been held at this conference earlier in the week demanding that governments around the world put access to HIV treatments and the global AIDS fund on the top of their policy agendas or risk being voted out of government and I also thought about the many HIV protests on other policy issues that I have been part of over the past twelve years. And while I whole heartedly support the calls for policy change made through these public protests, I couldn't help but feel sad that, as an injecting drug user, I couldn't even imagine gaining the same level of public support from people active on HIV/AIDS for a protest on the need for drug law reform to prevent HIV transmission amongst IDU. It made me realise that despite the policy work being undertaken by drug users and their supporters, until we have many thousands of people willing to put themselves on the line and publicly state their support for drug law reform change will be as far away as it has ever been and injecting drug users will continue to get HIV and will continue to be absent from the International AIDS Conferences.

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I would like to challenge everyone in this room who works in the area of HIV/AIDS and injecting drug use to think about how you could assist an active drug user to attend the next International AIDS Conference so they too can benefit from the knowledge and commitment for action associated with these conferences.