

The Role of People Who Inject Drugs in the Hepatitis C Response

Opening Plenary Presentation to the 4th Australasian Hepatitis C Conference

by
Annie Madden
Executive Officer
Australian Injecting & Illicit Drug Users League (AIVL)

I would like to begin by thanking the conference organisers for inviting AIVL to be part of the opening plenary today. As I have already said in my opening address, the Australian Injecting & Illicit Drug Users League (better known as AIVL) is the national peak body representing the state and territory peer-based drug user organisations and issues of national significance for people who use illicit drugs. This means of course, that AIVL and its member organisations also represent the vast majority of people affected by hepatitis C in Australia.

As many of you also know, I have been doing this, representing the voice of injecting drug users for a while now and it is probably fair to say that my days in the area are definitely numbered. The main reason for this is because representing drug users is hard work, it's hard to sustain your energy and commitment over long periods of time mostly because of the pressure – the pressure to convince people of your position, the pressure to constantly justify your very existence and your role in the area.

Today I have been asked to speak about “The Role of People who Inject Drugs in the Response to Hepatitis C”. My usual approach would be to stand before you and give an impassioned speech about ‘why’ the role of current or active drug users in the hepatitis C response is so important. But I’ve decided I’m not going to do that today. I’ve decided, that after ten years of talking at conferences like this one I am going to ‘go out on a limb’ and just take for granted that you already know ‘why’ the role of drug users in the hepatitis C response is so important. And furthermore, at the risk of being labeled ‘presumptuous’, I am also going to take it for granted that we (the Australian drug user movement) have your unqualified support when it comes to supporting the involvement of current drug users in the response to hep C.

What I would like to focus on for the remainder of my presentation is not ‘why’ we should involve injecting drug users in the response to hep C but ‘how’ to involve current injecting drug users in the response to hepatitis C. I should warn you upfront that this is not going to be a presentation that leaves people feeling warm and fuzzy. It is not my intention to offend or upset people but if you don’t feel up to hearing constructive feedback about the gaps and problems within the sector, then perhaps my presentation is not for you. With all that said, I like to begin...

How Soon is Now?

The hepatitis C epidemic is quite literally out of control amongst people who inject drugs. Despite an apparent decline in hepatitis C incidence amongst young injectors (which is a very positive thing), it is also true that more than 75% of people with newly acquired hepatitis C infections report a history of injecting drug use. Given this situation, no one could seriously argue that we have control over this major public health crisis for people who inject.

There are currently a number of major stumbling blocks getting in the way of developing an effective response to the hepatitis C epidemic not the least of which is the continuing lack of adequate, dedicated public health funding to respond to the epidemic effectively.

When HIV first threatened the Australian community, governments responded quickly and effectively. Large amounts of dedicated public health funding were made available to develop the kinds of responses necessary to contain this potential epidemic. This massive and co-coordinated effort resulted in a very low prevalence of HIV amongst injecting drug users in Australia.

The public health response to hepatitis C has been nowhere near as decisive and the profile of the epidemic has been far more complex. The fact that there was a large and growing hepatitis C epidemic amongst injecting drug users decades before the hepatitis C virus was even identified in the early 90's, means that responding to the hepatitis C epidemic has presented a very different set of challenges than those Australia faced in responding to HIV/AIDS.

In responding to hepatitis C we are taking on an epidemic that is well established and primarily affects a group of people who are extremely marginalised within society. In addition, by and large hepatitis C is not perceived as a major threat to the broader community. This is almost the complete opposite of what we faced with HIV/AIDS. Despite these clear differences however, we continue to expect that the responses and strategies established to address the HIV epidemic will somehow also "do the job" when it comes to controlling hepatitis C.

If we are really serious about stopping the further spread of hepatitis C amongst people who inject drugs then we need to get serious about the strategies that we are using to respond to the epidemic. Simply 'piggy-backing' hepatitis C prevention onto HIV prevention approaches is never going to be enough to stop the spread of a virus that is far easier to transmit than HIV and, unlike HIV, is already well established in the injecting drug using population.

As far as AIVL is concerned, one of the main missing ingredients in our current response to hepatitis C in Australia is the lack of genuine engagement with and involvement of current or active injecting drug users. There are a number of key areas that I believe we

need to focus on if we really want to engage with current drug users and understand the important role they must play in the response. These are:

- Improved Access to Primary Health Care for IDU;
- Changing the Hep C Diagnosis and Treatment Experience;
- Supporting IDU Hep C Peer Education; and
- Understanding and Supporting the Role of Drug User Organisations in the Hep C Response.

I now want to briefly look at each of these areas in turn.

Improved Access to Primary Health Care for IDU

AIVL is constantly involved in discussions about how we are going to “stop people who inject drugs getting hepatitis C”. But more recently we have started to realise that this is not the main question or the main issue. We realise that hepatitis C prevention amongst people who inject drugs is never going to happen while drug users don’t even have access to basic primary health care.

Drug users live with chronic pain, serious illness and poor general health as a routine part of life. They do not access primary health care services because of fear of how they will be treated (or not treated as the case maybe), or due to their inability to meet an array of ‘requirements’ and ‘criteria’ for these services. The barriers can include cost, the way a service operates, unavailability of treatments, attitudes and values of staff, geographic location, etc.

In short, many drug users cannot get their most basic health needs met and while this situation persists, hepatitis C will remain a low health priority for them and for that matter, for the system. People who inject drugs often just have more pressing and immediate concerns than hepatitis C. Think about it. If someone is about to lose their housing, is running a habit, has poor general, virtually no teeth left to eat with even if they had some money to buy food, lives in absolute poverty and has warrants out for their arrest - hepatitis C is not going to be their number one priority. If we want current drug users to put hepatitis C first, then we need to address their most basic needs first.

So how do we actually go about improving access to primary health care services for people who inject drugs? Well one way to achieve this is to develop health care services that meet the ‘actual’ needs of people who inject drugs rather than the needs or priorities that service providers and funding bodies think they should have. For example, many current drug users do not access general health care services because they either know that they cannot be honest about their needs and what is happening for them or if they do find the courage to be honest, they usually end up being punished or worse off somehow.

Current drug users routinely put up with severe pain and illness from injecting related problems because they know that if they are honest with a doctor about their injecting they risk losing takeaway doses if they are on the methadone program, scared that they may be investigated by DOCs if they have children or at the very least have a black mark against them that may come back to bite them if they are seriously ill down the track.

And if this wasn't enough to keep them away from general health services, the knowledge that they are extremely unlikely to be treated properly for any pain they may be experiencing ensures that current users generally make the choice to self-medicate with illicit drugs at best, and simply persevere with severe and chronic health problems at worst.

If primary health care services are genuinely interested in meeting the needs of current drug users then those services must:

- Make drug users feel welcome and treat people with basic dignity and respect;
- Create an environment where current drug users can be honest about their health issues without fear or punishment or their situation being made worse;
- Be affordable for people who simply do not have any money to spend on healthcare (the decline across the country in bulk billing has ensured that the majority of current drug users rarely access any health services outside of government run drug treatment programs and the handful of free health clinics);
- Have a minimum of 'red tape' including the ability to access services without a Medicare card;
- Be adequately funded so that they can provide appointments and quality services for everyone who needs to access them;
- Provide multiple services so that people can access all basic health services and some specialized ones in the one place;
- Take the service delivery out to where the client group is rather than expecting marginalized and disenfranchised people to come to them;
- Develop specialized services and/or programs for people whose needs are not currently being met by mainstream services such as indigenous drug users and young drug users;
- And perhaps most importantly, incorporate peer service delivery models into service so that people are greeted by a peer when they walk in the door, so that someone can go with them for support to referral appointments, so that they can talk to someone about safer injecting, finding veins, abscesses, etc, honestly and without fear.

These are just a few ideas, there are many more but if we are going to make significant inroads into hepatitis C prevention then we must improve the general health of people who inject illicit drugs. Only then will drug users be in the position to really prioritise issues such as hepatitis C in their lives.

Changing the Hepatitis C Diagnosis and Treatment Experience

Inextricably linked to the issue of improving access to primary health care is the issue of how current drug users get access to hepatitis C testing, diagnosis, monitoring and treatment. For many people who inject drugs, there is a large gap between their experience of hepatitis C testing and diagnosis and the principles outlined in the recently released National Hepatitis C Testing Policy.

The reason why an individual's hepatitis C testing and diagnosis experience is so important to the issue of engaging drug users in relation to hepatitis C is because how you are treated when you are tested and how hep C is framed when you are diagnosed dictates how you will see hep C from then on.

Whether you receive good pre and post test counseling (or *any* pre/post test counseling in too many cases), how your condition is described to you, the information you are or are not given, all influence whether you want to have anything further to do with the health system on this issue. All too often AIVL and its member groups hear stories of current drug users being told at diagnosis: "I have some good news and some bad news. The good news is you don't have HIV but the bad news is you do have hepatitis C." Comparing one condition to another is not helpful in anyway and only serves to confuse the patient and, in the case of hepatitis C, trivalise the whole issue.

I cannot tell you how many current drug users have told me that they received little or no pre or post test counseling when diagnosed and were basically told to "go home and forget about it". And we wonder why we are having so much trouble engaging current drug users on the issue of hepatitis C. These are people who are current injectors and they are being given no information on reinfection and no harm reduction information on preventing further transmission. While I am aware that we are not talking about all clinicians, the fact that it is happening at all is a disgrace. If we want drug users to take hepatitis C seriously, then we need to start with making sure that the health system takes it seriously.

When it comes to the issue of engaging current drug users in relation to hepatitis C treatment there are some major barriers that need to be addressed. As I have said in other forums recently, even if hep C treatments were to improve dramatically in the near future, it is unlikely to result in large numbers of current injectors accessing hepatitis C treatment because of a number of fundamental issues including:

- the way treatment is currently structured and provided does not encourage people who currently inject to come forward. As it current stands, the needs and issues of current injectors are an after-thought rather than the central focus when it comes to the way hepatitis C treatment is provided. Current drug users have to fit into the narrow dimensions prescribed for hepatitis C treatment or go without. Generally, there is very little effort made to accommodate the specific needs of current injectors into hep C treatment provision;
- the generally poor experiences that current injectors have with the health system does not encourage them to consider undertaking a lengthy, complex form of treatment that requires a highly supportive medical environment and a trusting relationship with your clinicians;
- the onerous criteria to qualify for treatment particularly the requirement for a liver biopsy are creating artificial barriers for current injectors wishing to access treatment. Despite changes to the guidelines for treatment access to supposedly

make treatment more accessible for people who inject drugs, these changes have not been widely translated into practice with many clinicians still very reluctant to treat current or active injectors; and

- the lack of any practical and useful links between drug treatment services and hepatitis C prevention, monitoring and treatment. The majority of large drug treatment programs (which see the majority of people in drug treatment) do not offer any form of hepatitis C prevention education, monitoring, treatment access or support. Many of these services do not view hepatitis C as part of ‘their role’ and as an issue that is too complex and time consuming. This means that many people with hepatitis C are regularly seeing the only healthcare provider that they are likely to have contact with, without anyone ever talking to them about hepatitis C. This needs to change.

We also need to address the attitudes of hepatitis C treatment providers in relation to providing access to hepatitis C treatment for active or current injectors. There seems to be a prevailing view that providing active injectors with access to a course of hepatitis C treatment is a ‘waste’ of scarce treatment places because “they will just go and get themselves reinfected”. But how do they know this?

While AIVL acknowledges that there are a number of valid reasons why you would want to ensure that people are entering treatment under the best possible circumstances for a successful treatment outcome, we do not accept that hep C treatment access should operate solely on the basis of whether people are actively using or not. There are now many studies that show average and in some cases above average levels of treatment compliance and adherence amongst active IDU when, not surprisingly, the treatment meets their specific needs.

AIVL believes that if harm reduction strategies and access to safe injecting equipment is seen as an integral part of hepatitis C treatment, and if there is a better quality of care and support specifically tailored to the needs of active injectors, then there is no telling the impact that successful hepatitis C treatment could have on a person’s life choices and future injecting behaviour.

Supporting IDU Hep C Peer Education

We know peer education is effective. But when you are fighting an epidemic the size of the hepatitis C epidemic you quite literally need an army of trained and well supported peer educators. Currently, across the country we only have a handful of trained peer educators whose priority focus is hepatitis C. We say we want people to be blood aware and to make sure that they inject as safely as possible every time – but who is making sure this happens? Who is funding the large numbers of IDU hep C peer educators to be out there, when people are injecting, making sure they know everything they can about hepatitis C prevention at the level of practical application?

The majority of people who inject may know the basics about hepatitis C, but there is a great deal of misinformation and myths circulating as well. People who inject drugs are very effective when it comes to passing on information to their peers. Contrary to government propaganda, the entire illicit drugs scene is based on the daily maintenance of extensive peer networks, sharing information, looking out for each other and helping each other to survive. The main problem we face is not encouraging people to share information but rather, making sure that the information that is in circulation is actually correct and useful. This is where the army of trained peer educators comes in. They are the people 'on the spot' who cannot only pass on new information but can also correct misinformation.

When we talk about 'the role of people who inject drugs in the hepatitis C response', there is simply no role that is as important as the peer educator. Peer educators are the people who are best placed to engage with other drug users on hep C, as we are often the only ones who are there when hepatitis C is actually transmitted - that is, when people are injecting. Health workers are generally not 'on the spot' when people are engaging in the behaviours that transmit hep C. We are 'on the spot' and we need to be supported to engage with and educate our peers effectively.

I am not talking about rocket science here. Too often we get caught up in discussions about "who is peer?" and "what is peer education?" rather than just funding the people who know what needs to be done to do their job. Sometimes I wonder whether the endless debates about peer education theory are just an excuse to avoid empowering current drug users to do things for themselves. Because when all is said and done, peer education is really simple. It is about supporting current drug users (and only current drug users) to keep doing what they are already doing with their mates – that is, sharing information when they are having a shot, or just hanging out together about the most effective way to swab your site, the safest way to inject, how to avoid other people's blood and how to clean up afterwards. It is also about supporting drug users to constantly improve their knowledge and the way they share information. And it's about resourcing peer networks to be able to support each other more, to have a voice and to have that voice listen to when it counts.

These days, just about anything passes as peer education and there is no shortage of experts on the subject. But at the end of day I believe there is only one group of experts when it comes to IDU hep C peer education and that is, people who currently inject drugs. Ex-injectors and non-injectors might be good educators, but they are not peer educators. Peer education is about ownership, trust, credibility, experience and knowledge. One of the main issues that is always overlooked in the discussions about 'who is a peer' and 'who is a peer educator' is that being a peer is not just about what you think and whether you see yourself as a peer but it is also about how you are seen by others – whether you are accepted as part of the peer group. This is not something that you can force or fake. You just know in your heart that you are a peer.

We don't need to be told how to do hep C peer education. We just need your support, resourcing and trust to do what we do best – educate and support each other.

Understanding and Support the Role of Drug User Organisations in the Hep C Response

Inseparable from the issue of the role of current drug users in hep C peer education is the issue of the role of peer-based drug user organisations in the hepatitis C response. I have no real idea how many of you are familiar with the concept of peer-based drug user organizations – I suspect many of you are, some of you think you are and a few of you are probably not familiar with the concept.

So, to make sure we are all on the ‘same page’ as they say, peer-based drug user organizations have been in existence in Australia for the best part of fifteen years. AIVL as the national body began back in the late 1980’s mainly in response to HIV/AIDS and miraculously managed to survive as an unfunded national network of organisations for over ten years before receiving some national hepatitis C funding in the late 1990’s which allowed us to establish the national office that we have today. AIVL currently has funded member organizations in every state and territory except Tasmania and also has unfunded activist-based organizations in the NT and SA along with the funded groups in those states/territories. AIVL and its member organizations refer to themselves as peer-based drug user organisation because we are run by and for people who use illicit drugs.

AIVL and its member organizations are acutely aware of how ‘unique’ we as organizations go, but to be perfectly honest our ‘uniqueness’ is more often than not used as a weapon against us rather than a reason to support and protect us. In the current highly conservative political environment, it is fair to say that peer-based drug user organizations are, by and large, barely surviving. Unfortunately, when it comes to the role that current drug users need to play in the hepatitis C response, ‘barely surviving’ doesn’t cut it. If we really want to drug users to take a key role in responding to the hepatitis C epidemic then drug user organisations have to do more than ‘just survive’ we have to grow and develop. And this is where all of you come in...

Everyone expects a great deal from drug user organizations in particular to do things that others can’t do, reach people that others can’t reach but there is rarely consideration of how difficult it is to undertake the role they do. Most people in the audience would have no idea how difficult it is to work in and/or be part of a drug user organisation. Drug user organizations are one of, if not, the most marginalized type of organization in the community. The people who work in drug user organisations have to constantly justify the existence of the organisation, they represent people who are highly marginalised and are engaged in illegal behaviours and to top it all off they are frequently people who drug users themselves. This means that the issues they are representing and fighting for are also personal issues including hepatitis C. It is not just a job or just another organization. When you are part of a drug user organization you don’t get to leave the issues at work – you get to *live* the issues.

So what do drug user organisations need to be able to play the role we want and need to play in relation to hepatitis C:

- We need to be adequately funded and resourced to represent and address the needs of the majority of the estimated 242,000 people living with hepatitis C and the many thousands not yet infected;
- We need to be treated as equals and respected for the expertise and professionalism we bring to the hepatitis C and related areas;
- We need to be supported (really supported, not just supported when things are going well but when things are tough and we are being attacked by the media and community merely because we dare not to be ashamed of who we are);
- We need to be trusted that we know what needs to be done, that our interest is promoting and protecting the health of drug users, that we have expertise and that we take a particular approach for a reason rather than being seen as people who, if left to their own devices, would have *everyone* injecting drugs tomorrow;
- We need to be supported to develop the skills and knowledge we need to be good peer educators and peer advocates and to run professional organizations; and
- Finally, we need to feel like we are seen as part of the solution not part of the problem – which we are so often made to feel (something difficult that everyone has to ‘manage’ but no one wants to own).

If drug user organisations are to play an effective role in relation to such a massive issue as hepatitis C amongst people who inject drugs, drug user organisations must have complete and total support - not part time support. We need recognition for the enormous amounts of work that drug user organisations have and continue to do, often unfunded, in relation to hep C. The reality is that current injectors aren't accessing other services and organizations in relation to hepatitis C because of fear, shame and stigma – if we are supported to do things for ourselves we can overcome these issues.

Say What Mean... Mean What We Say

This whole paper has been about the role of people who inject drugs in the response to hepatitis C. I just happened to be reading through the draft of the 2nd National Hepatitis C Strategy that has just been released for public consultation in the past few days. To my great surprise and I have to say anger, I found the follow statement in the draft strategy. It says that the Strategy:

“...seeks to prevent and reduce harm (to individuals and the community) while also encouraging addicts to ‘kick the habit’”...

Does the Federal Government and the Department think that calling us “drug addicts” is the best way to get people who inject drugs involved in the response to hepatitis C? For those of you who don't think this is such a big deal, I just want you to think about how you would like to be called a “drug addict”? The terms “drug addict” and “addict” have such negative connotations, are so stigmatizing and judgmental that that they simply have no place in any government documents let alone a national strategy on hepatitis C that says it is about partnership, involving affected communities and reducing discrimination, isolation and stigma experienced by people affected by hepatitis C.

When all is said and done such terms would only be used in a national hepatitis C strategy if you wanted to make the distinction between the “innocent” and the “morally corrupt” those who deserve to be infected with hepatitis C and those who got it through “no fault of their own”. Otherwise, why make the distinction? Does it really matter how people become infected with hepatitis C? All that matters is that people who are marginalized everyday of their lives due to their drug use do not have to feel that way when it comes to hepatitis C prevention, testing, diagnosis, treatment, care and support.

People who inject drugs are currently voting with their feet when it comes to accessing services in relation to hepatitis C. When the Australian health care sector decides it really wants to do something about involving people who inject drugs as partners rather than victims in the response to hepatitis C – you know where to find us.

Thank you.