AIVL

The Australian Injecting & Illicit Drug Users League
The national organisation representing people who use/have used illicit drugs

Stigma and Discrimination as Barriers to Health Service Access for People Who Use Drugs

EXECUTIVE SUMMARY

In Australia there is an acceptance that stigma and discrimination are social injustices that we should be overcome with significant public investment and high profile support as a democratic society that values respect, equality and diversity.

Despite this, stigma is maintained in our society against people who use drugs. It is written into laws and policies. It is the basis for many examples of discriminatory behaviour, some of which is seen as normal, standard practice by professional service providers. Stigmatising attitudes are used to deny people who use drugs access to basic standards and supports freely given to all others. It is unfortunate that this injustice is often interpreted as acceptable.

Unsurprisingly, many of the reasons stigma and discrimination are challenged in any other context remain consistent for people who use drugs. They form significant barriers to better health outcomes and consequently people who use drugs generally experience disproportionately poorer health. Often much of the work of health services is addressing the issues created by stigma and discrimination- all while little is being done to correct the root causes. This represents an unnecessarily high burden of health and impacts the whole community.

AIVL (the Australian Injecting & Illicit Drug Users League) is the national peak body representing people who use drugs. Informed by first-hand experience, we are not only intimately aware of the impact of stigma and discrimination, we have demonstrated that this expertise is crucial in the development of appropriate and effective responses to the many issues experienced by people who use drugs.

The stigma related to drug use can be understood as the conditioned negative attitudes, opinions and beliefs held by an individual that people who use drugs are somehow different to all other people.

In our community's context, discrimination occurs when people who use drugs are treated less favourably than others by another party based on that party's perception of our drug use.

To better understand these issues, AIVL will focus on defining what stigma and discrimination means to people who use drugs examine some of the barriers created by stigma and discrimination, including:

- Criminalisation and the impact of law enforcement
- Mis-framing our health issues and the disease model of drug use
- Lack of appropriate responses to harms we experience
- Discrimination in current standard practice of service providers
- Absence of anti-stigma initiatives

We see this as an important first step in enabling society to stand with us in challenging this human rights issue. AIVL acknowledges that rather than a complete account of our community's experience of stigma and discrimination this submission is the start of a conversation about how we can more safely and effectively support people in our community who use drugs.

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ABOUT AIVL

AIVL (Australian Injecting & Illicit Drug Users League) is the national peak body representing people who use drugs. Similar to other community representative bodies in Australia's highly successful response to Blood Borne Viruses (BBVs), AIVL and its state and territory member organisations are peer-based, meaning our staff are made up of people who have lived experience of drug use.

Our lived experience as peers is vital to community engagement and consultation. It creates a link between government and service providers, and the challenges faced by people who use drugs. This peer expertise supports better informed policy and legislative responses, and the development and implementation of health and social services that are targeted and effective.

The Australians who use drugs are immensely diverse. Regardless of the drugs used, the method and setting of consumption, whether treatment has been sought, the nature of use – dependent or recreational – or other demographics and circumstances, people who use drugs face common challenges inherent in criminalisation.

While AIVL has been primarily funded as part of the strategic response to blood borne viral illnesses, the strategic goals of the organisation include advocating for the health and human rights of all people who use drugs. The "Partnership Model" of government and services working with key affected communities in response to the HIV epidemic has led to Australia being recognised as a global leader in preventing and managing the transmission of HIV and Hepatitis C. Our achievements include maintaining a HIV prevalence among people who inject drugs at 1-2%, among the lowest in the world and the result of the meaningful collaboration with those who are often among society's most excluded.

This submission has been written in consultation with AIVL's member organisations to present a national voice for drug user organisations across Australia. At present AIVL's members are:

- Harm Reduction Victoria (HRVic)
- Hepatitis SA Clean Needle Program Peer Projects (HepatitisSA)
- Northern Territory AIDS & Hepatitis Council (NTHAC)
- New South Wales Users & AIDS Association (NUAA)
- Queensland Injectors Voice for Advocacy and Action (QUIVAA)
- Tasmanian Users Health & Support League (TUHSL)
- Western Australia Substance Users Association (WASUA)
- Canberra Alliance for Harm Minimisation & Advocacy (CAHMA)

These organisations provide a diverse range of services including needle and syringe programs, peer education, publications, counselling and support and clinical services. They are supported in this work by AIVL as a coordinating agency.

INTRODUCTION

WHO THIS IS ABOUT: "PEOPLE WHO USE DRUGS"

For AIVL, "people who use drugs" refers to our community as a whole (i.e. all people who use drugs), collectives of people who use drugs (i.e. peer based organisations), as well as individuals in our community. In this context, we also recognise the diversity of drug use in the community: from dependent daily use, to occasional and recreational use. We are also inclusive of the use of illicit drugs, including illicit use of pharmaceutical medication. We do not believe that the marginalisation created by legality, social acceptance, or socio-economic status is useful; as such we are inclusive of and recognise the human rights of all people who use drugs.

AIVL would like to acknowledge the complexity of the issue that is the stigma and discrimination faced by people who use drugs. We also wish to acknowledge the difficulty of engaging with people who experience intersecting stigma and discrimination and that we have not had the opportunity to engage with these people who have so often been left out of these discussions. While we have attempted to be as comprehensive as we can in this submission, we acknowledge that this is more of a start of a conversation, rather than a complete account of our community's experience of stigma and discrimination.

Finally, it must be acknowledged that this work is often hard to do for our workforce: peers - examining the bigotry that is present in our own lives in our work (such as the writing of this document) can potentially be emotionally impactful and highly distressing. Making this more painful is having to describe trauma that continues to have an impact upon ourselves, its widespread proliferation throughout our own community, and that there is little recourse available for us to correct this. At the same time, however, we recognise the importance of recording, documenting, analysing and communicating our community's experiences of stigma and that we are best placed to most accurately and authentically do this.

THE EXPERIENCE OF STIGMA AND DISCRIMINATION IN THE COMMUNITY OF PEOPLE WHO USE DRUGS

DISCRIMINATION

In our community's context, discrimination occurs when people who use drugs are treated less favourably than others by another party based on that party's perception of our drug use.

For this submission, AIVL not only aims to assert a definition of discrimination and stigma faced by drug users, we will strive to deepen this understanding by examining the various parts of this definition.

"… by another party…"

Discrimination is initiated from outside of the person who experiences it and can occur at different levels: during individual interactions (e.g. a conversation with an employer, or with a friends, or a staff member at a service); it can also be enacted by organisation or groups (e.g. engagement with agencies, services, and businesses); as well as being entrenched at systemic social level (e.g. policy makers pass discriminatory policy that allows stop and search powers that police then go on to enforce). For people who use drugs, experiences of discrimination at all these levels are so common, they can feel inescapable.

People who use drugs may become so accustomed to discrimination that many come to expect such mistreatment as the norm, with some in our community not even recognising the lower standard by which they are being treated. For others, awareness that one is being treated unfairly may be accompanied by the feeling that not much can be done about it. Whatever the perspective, AIVL is conscious of the high likelihood that all people who use drugs have experienced some degree of discrimination. We believe that working within our community to manage the effect of discrimination is highly important, but given that discrimination originates outside our community, AIVL recognises that much work must be done with broader community.

"… treated less favourably…"

Discrimination is manifested by an action or behaviour directed towards a person, the outcome of which is less positive, relative to the experience of general population or other community groups. Discrimination is observable, it can be recorded and the resulting outcomes can be quantified. It is this material difference that allows discrimination to be more readily recognised as a form of social inequity, leading to responses being established to prevent and address it in general contexts (i.e. anti-discrimination commissioners, equal opportunity law, etc.).

For people who use drugs, discrimination includes how society generally treats us as a group. For example, while the media may use respectful and non-judgemental language to refer to other marginalised communities, such practice is not typically applied when reporting on people who use drugs. Despite the unfairness of discrimination being demonstrable, the opinions, attitudes, beliefs and feelings that form the basis of discriminatory behaviour (i.e. stigma) are so pervasive and influential that this mistreatment seems normalised and, in many instances, is considered acceptable. As a result it often continues to go unaddressed. What can be inferred is that, at a fundamental level, these institutions believe this discrimination is acceptable, and both the lack or community outrage or formal regulatory response seems to support this belief. (AIVL would like to acknowledge that there have been a few instances where this has been challenged[1] though these remain quite rare.)

"… perception of drug use…"

[1] Such as recent cases brought to the Australian Press Council regarding the use of stigmatising and discriminatory language such as 'junkie scum' in reporting. See, for example, http://www.presscouncil.org.au/document-search/adj-1654/

Discrimination against people who use drugs is generally based on assumptions regarding a person's drug use, which may be current or past drug use. This perception may occur as a result of a person voluntarily disclosing their drug use (e.g. telling their GP) or via detection by police (e.g. in the course of being stopped and searched at a train station). It may not be involve an actual disclosure or confirmation of drug use at all, it may be assumed from a person's appearance, behaviour, a diagnosis and/or services they access. The first step for discrimination being targeted towards a person is the perception - or assumed perception - of their drug use.

To protect ourselves from the harm of discrimination, it has often been necessary for people who use drugs to prevent this perception of our drug use taking place. This behaviour includes hiding drug use from friends and family, not disclosing drug use to health care providers, not seeking help for issues related to their use such as financial hardship or struggling with withdrawal. When others learn of these behaviours of self-protection, they are often interpreted as deception, emphasising a maliciousness in the intent of such behaviour. AIVL urges a much more compassionate understanding of this behaviour, while we recognise the accountability of people who use drugs for their behaviour, we also believe that the broader community must also be accountable for the behaviour that is be driven by the stigma and discrimination.

As with all communities, the discrimination that we experience is unique and shaped by a number of factors:

- While many communities are protected to some degree by anti-discrimination legislation, people who use drugs have no such protection under the law in any Australian jurisdiction.
- The lack of protections for our community leads to the prevention of access to recourse to address instances of discrimination. While experiences of discrimination can be common among our community, accessing complaints procedures are far less likely, and even less unlikely are positive outcomes to complaints that have been formalised.
- Criminalisation alone is often seen as enough justification of discrimination, with no regard for a person's human rights, circumstances, or outcomes of such treatment.
- While recognition of the human right to bodily autonomy is making progress in public policy in various areas (such as abortion, sex work, and gender affirmation) this has yet to be extended to the use of illicit drugs by way of reform of current criminal sanctions.
- Regulatory standards of scientific accuracy, objectivity, benefit to the community, and respect for human rights generally inform law enforcement practice, however, these do not seem to apply for people who use drugs (e.g. the significant amount of evidence used to justify road-side alcohol testing, which quantifies intoxication in relation to an individual's ability to drive safely - compared to an absence of evidence demonstrating any effectiveness of the zero-tolerance based approach to road-side drug testing, which penalises a person regardless of how little drug is present in their system or their capacity to drive not being affected at all)

There is a tremendous diversity among people who use drugs. Some may experience multiple and complex needs, others may lead ordinary day to day lives. While a stereotype may be that we are all living in poverty, the fact is people who use drugs are represented in every socio-economic bracket. We are family members, friends, or co-workers and are of all ages, genders, races, and/or abilities. While some of us may be heavily impacted by discrimination, for others, this may be minimal. Much of the discrimination faced by people who use drugs arises from a failure to recognise this diversity. An example of this is the way opioid substitution dosing is provided, often requiring daily pick up during restricted times. There is an assumption that people who are dependent upon opioids are unemployed and, therefore, the negative impact of this requirement is underestimated. Indeed, many people have reported ceasing treatment based on the need to keep employment and family commitments. The current program structure does not allow for tailoring according to the needs of the person receiving treatment and often contributes to a whole range of additional negative impacts on a person's life.

STIGMA

The stigma related to drug use can be understood as the conditioned negative attitudes, opinions and beliefs held by an individual that people who use drugs are somehow different to all other people.

While discrimination can be observed as actions with quantifiable outcomes, the basis for this behaviour is stigma, and it is much less perceptible.

"… negative attitudes, opinions and beliefs…"

Because stigma is an internal cognitive process, it is difficult to perceive. These ideas may be expressed by the person who holds them or they may remain completely internal, undetectable and invisible. The stigma against people who use drugs is also so widespread, for our community it can feel as if we are constantly surrounded by people who feel negatively towards us every day. Due to the ubiquitous nature of this stigma, it is necessary that many of us be wary of all people with whom we come into contact. This apprehension can extend itself to our engagement with services; often the options we consider as viable are limited to the few we can establish as being safe for us to access through processes such as peer education and warm referrals. It must also be acknowledged that for some in our community, their circumstances may be that there are instances that present no safe available options (e.g. finding a local pharmacotherapy-dispensing chemist to in a rural setting where your privacy and confidentiality can be assured because everyone knows everyone). This is illustrates how stigma, despite being invisible, can form a significant barriers to opportunities, services and support.

"… conditioned…"

While stigma is cognitive process within an individual, it is also social phenomenon. Stigma is learnt behaviour, and is generally acquired via one of two ways:

1. it is either transmitted from one person via some sort of communication that is then believed by another (this includes one-to-one conversations as well as broadcasted messages, such as media articles); or
2. it may emerge as a negative response one may have during an interaction with a person who uses drugs, which they then generalise to all people in our community.

This stigma can then be reinforced via social processes. Like any learnt behaviour, there is potential to unlearn and deconstruct, to reframe, or to reverse stigma and its effect, replacing negative attitudes of exclusion and indifference with ones of acceptance and respect, shift the discourse from one that furthers marginalisation to one that critically examines how to support. This process has been seen with other communities, demonstrating the possibility that it can be realised for people who use drugs too.

However, the stigma experienced by people who use drugs is higher when compared to many other communities. The absence of any significant progress with regards to addressing this particular stigma (which is in stark contrast to the stigma experienced by, for example, people who experience mental health issues) seems to indicate a degree of social hesitation to let go of it. While the barriers created by stigma are being understood as a human rights issue for anyone who experiences them, unfortunately there seems to be a broad social acceptance that the stigma against people who use drugs is somehow necessary or deserved, that it is useful to discourage or control particular behaviours, that it demarks who is a "good person" versus who is a "bad person". If there are any benefits of such social control, they seem greatly undermined when one considers (as indicated by the 2013 National Drug Strategy Household Survey) that up to 42% of the national population have used illicit drugs in their lifetime - that is eight million Australians who could potentially experience the stigma against people who use drugs and the barriers it creates. A key body of work that is currently considered absent by AIVL is addressing the harmful social stigma held by the broader community against people who use drugs.

"… somehow different to all other people..."

Despite the widespread use of illicit drugs in Australia, the exclusion created by stigma associated with it is enduring. While it is acknowledged that problematic substance use does occur, the common typical reasons for a person's illicit drug use are not particularly abnormal, often these are comparable to the motivation for consuming legal drugs such as alcohol, tobacco or caffeine, e.g. to relax, to deal with stress, to celebrate an occasion, to manage pain or trauma, to have fun, to be more sociable, to enhance focus and performance, to deal with boredom, and so on. However, stigma acts in a way to create pervasive understandings of drug use as somehow separate to what is socially acceptable:

- Drug use is a moral failing, people who use drugs are bad people who deserve to be punished by law
- Drug use is a disease, people who use drugs are sick, of diminished capacity, and need treatment
- Drug use is high risk, people who use drugs are irresponsible so their lives are not as valuable
- Drug use is the cause of violent behaviour, people who use drugs are dangerous and must be controlled

From our experience, these beliefs, as generalisations of all people who use drugs, are all demonstrably false. While the use of illicit substances is often blamed for any number of social harms, often the problems associated with drug use can be traced back to other determinants of an individual's health, such as poverty, housing, education, access to social support, race, disability,-and, of course, the impact of stigma. While our community has known this for a long time, researchers are also starting to acknowledge this. In our view, by far the most significant social determinant of health for people who use drugs is the impact of criminalisation of drug use.

AIVL believes that one of the first steps to dismantling the stigma related to drug use is the understanding that drug use is "normal" human behaviour and that people who use drugs should be afforded the same respect, rights and protection as everyone else.

"… held by an individual…"

While discrimination is based on drug-use stigma that is held by one person against another, it is important to acknowledge that these negative attitudes, opinions and beliefs are so pervasive, they can also be held by people who use drugs, themselves, and this internalisation of stigma within an individual can be just as detrimental and significant. Feelings of guilt and shame can impact on mental health. Internalised stigma can act in a way that prevents or defers help-seeking; it may lead a person to feel that injuries or disease are deserved and therefore unworthy of assistance. This experience of stigma can be severely isolating, creating a distance between a person who is experiencing it and the support that may usually come from those who are close to them. The effects of internalised stigma can be heightened when one observes these negative attitudes being expressed in general discourse, such as in news reports or on social media. Internalised stigma is devastating to an individual; other communities who experience their own stigma have recognised this and have developed highly substantial responses to it. The most colourful example is Mardi Gras and the respective Pride Marches that are celebrated by the LGBTIQ community in each Australian state and territory. Fundamental to these events is pride - a direct counter-response to internalised stigma. While a parade may or may not necessarily be appropriate for people who use drugs, it's worth noting that such response to internalised stigma does not currently exist on any comparable scale.

SYSTEMIC BARRIERS IN THE HEALTH SYSTEM

The considerable stigma and entrenched discrimination that is experienced by people who use drugs is often most acutely felt in health care settings.

The following are a number of instances of stigma and discrimination being entrenched in the current Australian health system - often within services that are targeted towards or typically accessed by people who use drugs.

Criminalisation

By far, the most significant barrier to good health outcomes for people who use drugs is the criminalisation of drug use. Prohibition and law enforcement has had a far more negative impact on the health of people who use drugs, globally, than the harms present in drug use, while being ineffective at preventing or reducing the use of illicit drugs. We know that criminalisation - and the stigma that it carries - drives drug use underground and drives up the transmission of HIV and hepatitis C, overdose and death. We know criminalisation of drugs results in violence, social exclusion and breakdown of family and community. AIVL is part of the global movement to end the war on drugs and the people who use them and we call on the broader Australian community to be global leaders in this.

Further information regarding drug use as disease model is discussed in "A war on the health of people who use drugs" within the Annotated Bibliography of published articles

The harms associated with criminalisation of drug use are felt here in Australia too. One of the most severe forms of discrimination that criminalisation creates is the relationship between people who use drugs and the police. For most other groups in the community, police provide the role of protector but, for people who use drugs, police represent a risk to safety. This is acutely significant for people who use drugs who experience a heightened vulnerability to crime and violence, such as women, children, people who are older, people living with a disability.

In addition to the police, criminalisation compromises the relationship between people who use drugs and health care providers. Anecdotal reports from people with a history of injecting drug use and drug dependency also confirm the ongoing pressure of having outstanding warrants, legal matters, court appearances and imprisonment as some of the factors that have led people to 'de-prioritise' their health generally and issues like hepatitis C in particular.

The impact of criminalisation itself is extensive and is briefly summarised in the following list:

- Automatically creates a 'criminal class' of people – those who use or have used illicit drugs;
- Creates and re-enforces the regulation and control of those substances by the 'black market';
- Artificially inflates the cost of those substances so that people are forced to take greater and greater risks to get the money to buy them;
- Can lead to people who would otherwise have not had any contact with the criminal justice system committing a host of 'drug-related' offences often out of desperation;
- Makes people vulnerable to police attention and discretionary powers;
- Drives people away from family, community, information, services and support;
- Removes choice – in all aspects of life including health;
- Forces people to withhold or change information due to fear of the consequences of being honest;
- Drives people to take greater risk with injecting practices making them more vulnerable to BBVs;
- Leaves people vulnerable to sensationalist, inaccurate and invasive media reporting;
- Increases the likelihood of having children removed on the grounds of drug use alone;
- Results in people being unable to get or keep employment due to past criminal record or inflexible drug treatment programs;
- Leads to poverty and social exclusion;

- Allows poor, inequitable and inhumane treatment to go unnoticed and unreported due to fear and/or because people see themselves as 'deserving' such treatment; and
- Results in people handing over their power, their rights and their dignity in exchange for access to basic services.

Further information regarding drug use as disease model is discussed in "Impact of Illegality and Criminalisation" within the Annotated Bibliography of published articles

<u>Mis-framing of presenting health issues of people who use drugs: The disease model of drug use</u>

Conceptualising drug use as 'addiction' or a health issue has been challenged by many as being based in stigmatising believes and understandings. This has particular implications for the health system.

Characterising drug use as 'disease' (i.e. some deviation from normal body functioning that has undesirable consequences for the affected individual) is convenient as it fits with a medical model approach that the alcohol and other drug (AOD) sector favours. One of the most common ways drug use is characterised as a disease is by labelling it as 'addiction'.

When one considers the behaviours that many consider related to "addiction", a diverse range of experiences may be included such as:

- Regular, physically dependant consumption
- The avoidance of physical symptoms associated with withdrawal
- Experiences of conflict regarding the positive and negative effects of drugs
- The inability to get out of bed in the morning, or to achieve good sleep, without consumption
- The inability to engage with day to day tasks, such as work, without consumption
- Impulsive, seemingly uncontrollable, or chaotic use of substances
- Compulsive use, without which anxiety and the inability to function may result
- A coping mechanism for another physical or psychological problem (self-medicating)
- Feeling that one can only engage in particular activities (e.g. socialising) with consumption

This short snapshot is by no means complete, however, it illustrates a range of issues a person may present when attending an 'addiction service'. While these services may be responsive to presenting issues directly related to substance dependence, it can be a frustration for people who use drugs that the problem they seek assistance for is not necessarily addressed by these services. . As previously stated, while the cause of problems related to drug use may be other determinants of health, perceiving drug use as a disease may lead one to only seek health or medical interventions, where perhaps their issues may be better addressed with more social and community support. In other instances, some dis-entanglement of personal issues may be required in order to determine whether the presenting issues of a person seeking help is caused by their drug use or whether drug use is actually a symptom of it. Whatever the issue is for the individual, AIVL is not supportive of the current use of the term 'addiction' as a blanket description of many of the issues related to substance use as it is not specific enough to effectively describe the experiences of all people who use drugs and can also have the effect of negatively homogenising these experiences.

In addition to mischaracterising an individual's drug use, the 'drug-use as disease' model also limits the range of health interventions available to people who use drugs. The medical model strives to find a 'cure' and there is a tendency within the drug and alcohol sector to apply this approach to people who use drugs. Abstinence- focussed interventions that identify 'recovery' as a goal may be appropriate for some people but this may not be a realistic or even appropriate aim for all people who use drugs. From our experience, we know that people who use drugs seek a health response in relation to a whole range of issues, including acute health incidents (e.g. a venal abscess from a missed injection), advice regarding the prevention of BBV transmission, support to reduce one's drugs use to a manageable level, reducing drug related harm without ceasing use altogether. Yet abstinence-focused AOD services dominate the health landscape, so much so that for some people who use drugs, it can feel like there is nothing else out there.

AIVL acknowledges that issues of substance dependence are a reality and interventions for these should be made much more available than they currently are. To clarify this understanding, AIVL recommends not using the word 'addiction', instead preferring the term 'drug dependency' to describe people who require regular use of a substance in order to avoid withdrawal symptoms.

AIVL also recognises that for many people, drug use is not a problem at all andthat for the majority of people who use drugs, their use is does not disrupt their lives, does not have negative consequences and often enhances experiences.

Further information regarding drug use as disease model is discussed in "New Recovery, Harm Reduction & Drug Use Policy Statement" within the Annotated Bibliography of published articles

Lack of appropriate responses

A weakness of the medical model when it comes to drug use, even in the treatment of drug dependence, is that it cannot adapt fast enough, and in many instances, attempt to implement established 'cure' methods to all forms of what it considers a disease. This can be observed in the lack of effective treatment for methamphetamine dependency.

Previously, it was believed even among people who use drugs that methamphetamine was not a drug of dependence - much of this this drawn from the lived experience of methamphetamine use being very different to other drugs, namely heroin, which had more physically demonstrable indicators of dependence. However, as drug trends change, our intimate understanding of dependence has evolved along with it to recognise mental health and social symptoms of dependence. The service system, however, has not been so adaptive, with reports of a lack of available beds and long waiting lists, and people seeking help and their families paying exorbitant amounts of money to enter private clinics. A bigger barrier still is the questionable effectiveness of rehabilitation services for methamphetamine use - one criticism is that services are inappropriately using an approach responsive to heroin dependence for those experiencing issues with methamphetamine.

The media focus on methamphetamine use has created pressure on governments to respond, which leads to inappropriate approaches being adopted and for stigma to be heightened. This is where AIVL's unique position of coming from the BBV sector demonstrates its value. Our organisation knows the value of harm reduction and peer education, we have practiced it to maintain a HIV prevalence amongst people who inject drugs of 1-2%. We know that an approach that is focussed on the meaningful involvement of the affected community and addresses issue of the social determinants of health is effective and that the drug and alcohol sector could learn from the approach taken in the BBV sector.

Discrimination in current standard health practice

Due to stigmatising behaviour people who use drugs often experience a standard of health care that is different to that experienced all other health consumers. This is clearly illustrated by the current model of pharmacotherapy treatment across Australia.

Opioid Substitution Therapy (OST) (in Australia this is limited to methadone, suboxone, buprenorphine) is highly effective in providing a degree of stability for people experiencing opioid dependence. These medications are listed as Section 100 (Highly Specialised) medication and are regulated by particular state restrictions, however, current standard practice dictates that:

- They must be prescribed by a licensed doctor
- Prescribing doctors must apply for a permit for each patient
- They are only dispensed by particular pharmacies, which is specified for each patient at application
- Medication is dispensed daily
- Despite the medication being fully subsidised by the Australian government a cost is usually attached to dispensing and charged directly to the patient for which there is no concession - this can be up to $10 per day
- Doses that can be taken away from the pharmacy are determined at the discretion of the prescriber

No other medication is regulated so rigorously, and it's hard to describe this regime as anything but discriminatory. The regulation of OST is applied in a highly inflexible way, research has documented the negative impact this has had on patients- including the involuntary discontinuance of therapy and having to forego basics such as food and accommodation in order to pay dispensing fees. AIVL considers that the current pharmacotherapy regimes are urgent need of overhaul in order to address this discrimination.

Further information regarding drug use as disease model is discussed in "A raw deal? Impact on the health of consumers relative to the cost of pharmacotherapy" within the Annotated Bibliography of published articles

Absence of anti-stigma campaigns

Despite the significant barriers created by stigma and discrimination for people who use drugs, there is currently no national, systematic campaign currently in practice to address it. When one considers that anti-stigma campaigns that exist for mental health, HIV, and STIs are resourced by significant amounts of health funding, no such response currently exists for drug use. In such a context, addressing many of the barriers to good health outcomes will continue to be a challenge. AIVL has observed the efforts made by our colleagues in the HIV sector and believes similar investment in health promotion campaigns that target stigma and discrimination against people who use drugs are urgently needed as a first step to addressing this issue.

Annotated bibliography – Published Articles

'Why wouldn't I discriminate against all of them?' A report on stigma and discrimination towards the injecting drug user community (AIVL)

Publication details

Australian Injecting and Illicit Drug Users League (AIVL) 2011, 'Why wouldn't I discriminate against all of them?' A report on stigma and discrimination towards the injecting drug user community, Canberra, Australia.

Hyperlink [HTTP://WWW.AIVL.ORG.AU/RESOURCE/WHY-WOULDNT-I-DISCRIMINATE-AGAINST-ALL-OF-THEM-A-REPORT-ON-STIGMA-DISCRIMINATION-TOWARDS-THE-INJECTING-DRUG-USER-COMMUNITY/](http://www.aivl.org.au/resource/why-wouldnt-i-discriminate-against-all-of-them-a-report-on-stigma-discrimination-towards-the-injecting-drug-user-community/)

Key findings

- This document outlines the development of drug use, from its perception as a matter of personal taste to its being seen as a 'disease' during the Industrial Revolution.
- With changing times, drug use became firmly placed in the criminal justice system, and today it uncomfortably straddles both the medical and the criminal justice spheres.
- An unacceptable number of the world's citizens are being penalised by the current drug laws and the amount of harm that befalls people who inject drugs is inhumane—HIV/AIDS, hepatitis, tuberculosis, overdose, imprisonment, and so on.
- Discrimination against drug users—particularly those who inject—is one of the final bastions of legitimised discrimination. It must be tackled on numerous levels:
    - through government and our adherence to inappropriate international treaties • through the criminal justice system and laws that are allowed to remain in the statute books
    - through the medical profession because of the inability of some its members to observe the Hippocratic oath in relation to individual drug users and their health needs
    - through the mass media that deliberately misrepresent drug users in the interest of higher ratings and greater profits
    - in the education of every individual who jeers at or berates drug users while knowing nothing about them and happily indulging in their own drug of choice.
- We outline in this document how drug use and drug users have come to be stigmatised through various processes and over time.
- We look at the current theories of stigma and discrimination and how they affect drug users' health.
- We discuss the development of the stereotype of the injecting drug user and how the media influence public opinion and ultimately drug users' health through governments' development of overblown public policy.
- We take those stereotypes and show how the general community and the medical profession use them to discriminate against drug users.
- Finally, we discuss how drug users are aware of what society thinks of them and the consequences of this for their self-esteem and their ability to gain access to adequate health services.

Recommendations

Legislation and policy

International

- that the Commission on Narcotic Drugs and the UN Office of Drugs and Crime be called on to ensure that all international drug control laws and policies are consistent with accepted international standards in relation to human rights and the right to health for all
- that UN agencies be encouraged to review all relevant UN policies and programs to ensure they actively support and implement the principles of the meaningful involvement of people who use drugs
- that the International Network of People Who Use Drugs and regional drug user networks work together to highlight the impacts of illegality and criminalisation and of stigma and discrimination on the health and human rights of people who use drugs, with a view to encouraging legislative and policy reform to redress these impacts
- that AIVL work with the International Network of People Who Use Drugs in its efforts to encourage the meaningful representation of people who use drugs on all relevant UN bodies—such as the Technical Advisory Group for the Global Commission on HIV and the Law—dealing with questions of legal and policy significance to our community.

National

- that the Australian Government identify, review and, as appropriate, repeal federal laws and policies that contribute to the continuing criminalisation and marginalisation of people who inject illicit drugs
- that the Australian Government support investment in peer-led social research initiatives aimed at documenting and improving our understanding of the impact of laws and policies that stigmatise and discriminate against people who inject illicit drugs
- that Australian Government agencies responsible for curriculum development in Australian universities institute a policy mandating that all university-level courses in medicine, nursing, pharmacy and dentistry include content on reducing stigma and discrimination against people who inject illicit drugs.

States and territories

- that state and territory governments be called on to identify, review and, as appropriate, repeal laws and policies in their jurisdiction that contribute to the continuing criminalisation and marginalisation of people who inject illicit drugs
- that each jurisdiction carry out a jurisdiction-wide review of the policies and practices associated with needle and syringe programs, opioid pharmacotherapy programs and other major health services used by people who inject illicit drugs, with the aim of reducing stigma and discrimination and improving health service access for this group.

Community education

International

- that it work with the International Network of People Who Use Drugs, at the global, regional and national levels, to take advantage of relevant international forums and events to raise awareness of stigma and discrimination associated with people who inject drugs
- that it work with the International Network of People Who Use Drugs to develop for the World Health Organization, UNAIDS and other global agencies a media guide on how to refer to people who inject drugs in their communiqués and other online and print-based publications
- that it work with the International Network of People Who Use Drugs and Harm Reduction International to develop an international media awareness and awards program that celebrates appropriate media behaviour. Award recipients could be announced at the International Conference on the Reduction of Drug Related Harm or another suitable international forum
- that media complaints units around the world take a firmer stance on the stigmatisation in the media of people who use drugs

- that the International Network of People Who Use Drugs and other international drug user organisations work together to more effectively use current media—such as Facebook, Twitter, current affairs programs and newspaper articles—to give a more balanced account of drug-related matters.

National

- that the findings from this document and the AIVL anti-discrimination market research report be used to develop a multi-stage general community education campaign beginning in July 2011 to start the process of responding to the causes of stigma and discrimination associated with people who inject drugs
- that social research be carried out in order to develop a better understanding of other highly marginalised groups and the strategies they have developed for dealing with and overcoming stigma and discrimination in their community
- that AIVL seize opportunities to present papers or research results at relevant national forums and other events in order to raise awareness of stigma and discrimination against people who inject drugs
- that AIVL develop a national media guide to improve the quality of reporting in relation to illicit drugs and to reduce the stigma and discrimination associated with people who inject drugs
- that the National Drug and Alcohol Awards include a media awareness and award program that salutes appropriate media behaviour in relation to reporting on illicit drug use and people who inject such drugs
- that federal parliamentarians receive education about the health and human rights of people who inject drugs and how current approaches to drug control adversely affect the health and wellbeing of people who inject drugs on a daily basis
- that the Australian Communications and Media Authority be encouraged to take a firmer stand on the reporting of matters that reinforce negative attitudes and perpetuate stigma and discrimination associated with people who inject drugs
- that the importance of the concerns identified in this document be emphasised through further development of AIVL's mass media communication approaches—for example, the website and Facebook and Twitter.

States and territories

- that its state and territory member organisations take advantage of relevant local forums and events to raise awareness of stigma and discrimination associated with people who inject drugs
- that it assist state and territory member organisations in the dissemination of a national media guide, with the aim of improving the quality of reporting in relation to illicit drugs and reducing stigma and discrimination associated with people who inject drugs
- that its state and territory member organisations lobby jurisdiction-based communications and media authorities to take a firmer stand on the stigmatisation of people who inject drugs
- that its state and territory member organisations educate their members of parliament in how the current jurisdiction-based drug control laws negatively affect the health and wellbeing of people who inject drugs on a daily basis.

Peer empowerment

International

- that it work with the International Network of People Who Use Drugs to ensure that people who inject drugs globally are informed of their rights and come to recognise stigma and discrimination for what they are—ways of diminishing and punishing us

- that it work with the International Network of People Who Use Drugs' global programs to develop tools that empower people who inject drugs to fight stigma and discrimination.

National

- that it help its member organisations in individualising existing peer-run self-empowerment tools and programs so these tools and programs more clearly relate to the local situation
- that at AIVL general meetings and other events attended by people who inject drugs national training sessions be conducted in order to promote the findings and recommendations of this document and AIVL's national anti-discrimination market research report
- that AIVL's range of policy initiatives and publications (including this document) on stigma and discrimination among people who inject drugs be promoted on the AIVL website and through links with other online forums
- that AIVL continually promote and update its new online anti-discrimination reporting site as a central aspect of recording people who inject drugs experiences of stigma and discrimination and informing AIVL and its members in developing effective responses.

States and territories

- that state and territory peer-based drug user organisations be supported to develop and run self-empowerment groups within their local community of drug users
- that AIVL work with its state and territory member organisations and their clients to use and promote the new AIVL online anti-discrimination reporting site in order to reduce stigma and discrimination associated with people who inject drugs.

Professional societies and workforce development

International

- that members of all relevant professional societies and staff of government agencies be encouraged to read the international version of Nothing about Us Without Us to improve their understanding of the importance of the meaningful involvement of people who use drugs
- that AIVL support the International Network of People Who Use Drugs in international workplace development projects aimed at reducing hepatitis- and HIV-related stigma and discrimination against people who inject drugs.

National

- that the Australian Government Department of Health and Ageing take a leadership role in ensuring the implementation of the current national blood-borne virus and sexually transmissible infection strategies in relation to reducing stigma and discrimination and improving the health and human rights of people who inject drugs
- that there be an audit of workforce practices in relation to stigma and discrimination in organisations that provide services for people with a history of injecting drug use—including government agencies, hospitals, and other important health and social services
- that the recommendations of the C-Change report into hepatitis C–related stigma and discrimination be implemented as a matter of urgency
- that AIVL, in consultation with its member organisations, develop a national training module dealing with stigma and discrimination against people who inject drugs for inclusion in university courses in the areas of medicine, nursing, pharmacy and dentistry and in police training

- that AIVL support and, where possible, collaborate with the Australasian Society for HIV Medicine in any healthcare-related workplace development projects the society undertakes targeting stigma and discrimination against people who inject drugs
- that social research be conducted into the most effective ways of helping healthcare workers recognise and deal with institutional and individual discrimination against people who inject drugs
- that the findings and recommendations of other AIVL publications that specifically deal with stigma and discrimination among people who inject drugs be promoted to a range of relevant workforces. Among these publications and their proposed targets are the following:
    - Hepatitis C Models of Access and Service Delivery for People with a History of Injecting Drug Use
    - for promotion to hepatitis C service providers such as tertiary liver clinics, general practitioners and other relevant health services
    - Legislative and Policy Barriers to NSP for People Who Inject Drugs
    - for promotion to all needle and syringe programs, alcohol and other drugs organisations, police services, relevant government departments, and federal and state and territory parliamentarians
    - Treatment Service Users (TSU) Research Project (Phases 1 and 2)
    - for promotion to drug treatment services such as opioid pharmacotherapy, residential rehabilitation, detoxification and counselling services
    - the Older Injecting Opioid Users discussion paper
    - for promotion to all relevant health and social services
    - the National Statement on Ethical Issues in Research Involving Injecting/Illicit Drug Users
    - for promotion to all relevant national research organisations and relevant individual researchers.

<u>States and territories</u>

- that its state and territory member organisations be supported in tailoring the AIVL national training module on stigma and discrimination associated with people who inject drugs to suit specific local workforce development needs and circumstances
- that it work with its state and territory member organisations to ensure the implementation of the national and state- and territory-based blood-borne virus and sexually transmissible infection strategies in seeking to reduce stigma and discrimination and improve the health and human rights of people who inject drugs
- that it ensure that all state and territory member organisations receive multiple copies of all AIVL publications dealing with stigma and discrimination associated with people who inject drugs for dissemination and promotion at the local level.

Drug User Peace Initiative: Stigmatising People who Use Drugs (INPUD)

Publication details

INPUD, Drug User Peace Initiative: A War on the Health of People who Use Drugs, 2014,

For more information about the Drug User Peace Initiative visit http://www.inpud.net/en/news/drug-user-peace-initiative-relaunch-docs

Hyperlink http://www.druguserpeaceinitiative.org/dupidocuments/DUPI-Stigmatising_People_who_Use_Drugs.pdf

Key findings

- Criminalisation produces many of the harms associated with drugs; prohibition cynically uses these harms, making use of circular logic to justify itself.
- Drug classification and criminalisation is, in essence, discriminatory, unscientific, and arbitrary.
- the widely-held, generalising, and unscientific position that illicit drugs are 'bad' informs the understanding that people who use drugs are bad too
- Much of stigma is carried through language
- The term 'addiction' is not neutral: it has specific, problematic meanings and connotations. In fact, the World Health Organisation called for an end to the use of the term 'addiction' as early as the 1960s.
- People who use drugs are simultaneously feared as being unpredictable and violent, whilst also being pathologised, pitied, and disempowered as being mentally and physically sick and unable to make decisions about their own lives
- Because people who use drugs are criminalised and stigmatised, discriminatory language, drug shaming, and defamation are accepted and commonplace. The fact that offensive and discriminatory media reporting usually passes without critical mention or complaint serves to highlight how deeply userphobia is ingrained.
- For people who use drugs, staying hidden and passing as someone who does not use drugs and/or concealing their drug use in certain contexts is often necessary in order to survive.
- Stigma serves to isolate and alienate people who use drugs from service and healthcare provision, reducing opportunities for education, outreach, and peer networking.
- Coming out as a drug user to healthcare and service providers often results in problematic interactions.
- There is discrimination against harm reduction interventions, services designed to mitigate and reduce the harms that can be associated with drug use. This is driven by stigmatisation of people who use drugs and by a moralisation of drug use

Recommendations

This report was prepared as an advocacy document to used in the lead up to UNGASS 2016

A RAW DEAL? THE IMPACT ON THE HEALTH OF CONSUMERS RELATIVE TO THE COST OF PHARMACOTHERAPY (JAMES ROWE)

PUBLICATION DETAILS

Rowe J. A raw deal? A raw deal? Impact on the health of consumers relative to the cost of pharmacotherapy RMIT, 2008

HYPERLINK http://www.salvationarmy.org.au/Global/News%20and%20Media/Reports/2008/4-raw-deal-book.pdf

KEY FINDINGS

That opioid maintenance treatment is one of the most successful treatment interventions for problematic and / or dependent illicit opioid users;
That opioid maintenance treatment provides opioid dependent individuals with the stability needed to address issues such as housing and health – as well as underlying issues that may contribute to their drug use in the first instance;
That opioid maintenance treatment leads to, at best, to cessation of illicit opioid use and, at worst, a significant reduction in illicit opioid use;
That opioid maintenance treatment produces the best outcomes, for client and community alike, the longer that a client is retained in treatment;
That the need to pay regular dispensing fees is an obstacle to entering, and remaining in, opioid maintenance treatment. This is especially the case for those on government income support;
That the Pharmaceutical Benefits Scheme (PBS), as regulated by Part VII of the National Health Act 1953, discriminates against those on opioid maintenance programs by failing to subsidise dispensing fees for those on programs;
That clients often prioritise the payment of dispensing fees over basic necessities, including food and accommodation;
That income-poor clients are compelled to rely on emergency relief services to meet food and accommodation needs;
That a significant minority of clients engage in illicit sex work and acquisitive crime to meet the financial obligations of their treatment (i.e. dispensing fees);
hat the difficulties meeting the financial obligations of opioid maintenance treatment often contributes to a deterioration in the relationship between dispensing pharmacist and client;
That the accumulation of debt through the inability to pay dispensing fees is a primary reason for the involuntary discontinuance of treatment;
That dispensing fees are the single greatest obstacle to retention in opioid maintenance treatment;
That the withholding of opioid maintenance pharmacotherapies encourages illicit heroin and / or other opioid use;
That involuntary discontinuance of treatment is invariably followed by a return to problematic heroin use.

RECOMMENDATIONS

Recommendation 1: That pharmacists receive fair remuneration for the dispensing of opioid maintenance programs as prescribed by the Commonwealth-regulated Schedule of Pharmaceutical Benefits ($8.15). This would go some way towards addressing the reluctance of many pharmacies to participate in the scheme and to covering losses incurred through bad debt (which would be expected to decline significantly under a subsidised program).

Recommendation 2: That, in the interests of equity, individuals who are on opioid maintenance programs are treated no differently than any other individual receiving prescribed medication for a diagnosed health problem. Federal discrimination in the form of PBS arrangements that place the burden of dispensing fees on consumers are not justifiable from a human rights perspective.

Recommendation 3: That the Commonwealth Government amend the Pharmaceutical Benefits Scheme to include methadone, buprenorphine and buprenorphine / naloxone combinations alongside other medications in Section 85 of the National Health Act 1953. The cost represented by this amendment would be easily outweighed by the savings to the Commonwealth, State and Territory Governments across Australia.

Recommendation 4: As an emergency interim measure, the Victorian Government immediately move to extend the subsidisation of opioid maintenance programs from those under the age of 18 and those subject to Juvenile Justice Orders to all financially vulnerable clients (i.e. those with health care cards).

We Live With it Almost Every Day of Our Lives - An AIVL Report into Experiences of Stigma &Discrimination (AIVL)

Publication details

Australian Injecting and Illicit Drug Users League (AIVL) 2015, We Live With it Almost Every Day of Our Lives - An AIVL Report into Experiences of Stigma &Discrimination, Canberra, Australia

Hyperlink http://www.aivl.org.au/wp-content/uploads/20151008_Report-Web.pdf

Key findings

The AIVL discrimination survey has been available since 2012 having been disseminated through AIVL's website, as well as in hard copy through AIVL's member organisations in each state and territory. This paper is a review of the first 265 responses sharing a broad range of experience of discriminatory behaviour suffered by respondents across genders, ages, and in many distinct settings, comparing survey results collected in 2015 with those from 2012.
The overall demographics

- Male (55) and female (43) respondents were generally equally represented, with 2% identifying as either transgender
- Those aged 26 through to 45 represented more than 65% of respondents; those between 46 and 59 years of age at 26%; with those over 60 represented at around 2%.
- Younger people have been increasingly represented with a jump from 1.2% in 2012 to 5.3% in 2015 from respondents aged 19 to 25.

Reported incidents according to states/territories are as expected considering relative populations:

- Nationally the majority of reported incidents overall (69%) occurred in metropolitan settings,
- However incidents being reported from regional and rural areas have increased by 10% during the survey period to date (25.3% and 5.4% of respondents nominated these localities – that is in regional/rural areas outside of metropolitan centres – respectively).
- All states and territories are represented in the data-most reports were received from Queensland 34.4%, NSW 18.8% and Victoria 12.6%

Experiences of Discrimination

- The most common setting for discrimination were healthcare providers: Hospitals 48.1%, Doctors' clinics 47.3%, Pharmacy 38.5. Police were also identified by 39.7% of respondents
- Respondents primarily believed that they were discriminated against because they were injecting drug users or perceived to be 73.3%, or because they were on pharmacotherapy 42%; although having HCV was also highly nominated in the survey responses 27.1%.
- *Disclosure* of drug use or BBV status led to their being discriminated against.
- Discrimination led to feelings of anger, alienation, fear, and shame, as well as dramatically increasing levels of stress (often at times when the respondent was seeking help due to matters that themselves were enormously stressful); suicidal ideation amongst respondents was not uncommon.
- A common consequence of being discriminated against was refusal of service such as pharmacotherapy or pain relief, breaches of confidentiality, loss of employment, and the loss of custody of their children.
- The majority of respondents said that discrimination was something they had experienced on more than one occasion.
- And the majority of respondents said that they had not bothered with following through with any formal complaint process because they often believed that it would do (them) more harm than good.

New Recovery, Harm Reduction & Drug Use Policy Statement

Author: AIVL

https://www.afao.org.au/library/topic/injecting-and-illicit-drug-users/New-Recovery-Harm-Reduction-Drug-Use-AIVL-Policy-Position-Paper.pdf

Publication details

AIVL Australian Injecting & Illicit Drug Users League (AIVL) New Recover, Harm Reduction & Drug Use, June 2012

Hyperlink if available

Key findings

AIVL is not anti-abstinence we support people being able to choose the drug treatment approach that is best for them and their particular circumstances.

AIVL does not support 'disease-based' models or 'genetic theories' of drug use.

AIVL believes that false distinctions between 'active users' and 'people in recovery' are unhelpful and may promote continued social exclusion and stigma and discrimination against current drug users.

AIVL advocates the harm reduction approach as an essential element of an evidencebased, ethical and effective response to addressing licit and illicit drugs.

AIVL rejects the use of simplistic slogans such as "Treatment Works" and supports a more sophisticated analysis of when, how and why we would claim that treatment is working for those in treatment or those who have been in treatment.

AIVL only supports AOD and/or BBV approaches or models that involve genuine informed consent, treatment choice, consumer participation and respect for fundamental human rights.

AIVL believes people on opioid pharmacotherapy maintenance potentially stand to lose and suffer the most from any shift towards a 'new recovery' approach that advocates the removal of opioid pharmacotherapy maintenance or in any way resembles the current UK Government endorsed "full recovery" paradigm.

AIVL does not support the use of the term "recovery", "new recovery", "full recovery" or any other variation of the above to replace "harm minimisation" as the way to describe the overarching philosophy or policy framework underpinning the Australian AOD and BBV sectors.

AIVL believes if "new recovery" advocates are actually seeking a commitment to abstinence-based approaches alone, then it should be said openly and we should have a full and frank discussion about the implications and relevance of such an approach in the Australian context.

AIVL does not believe it is necessary to attempt to 'cherry pick' the best of 'new recovery' and harm reduction approaches to create a uniquely Australian 'recovery based' approach. The current Australian AOD treatment approach already offers a range of treatment modalities.

AIVL questions whether the 'new recovery' approach is actually 'new' as the current Australian AOD drug treatment system already includes a range of services and programs based on a 'recovery' oriented approach.

AIVL does not support the use of "Payment by Results" type funding models for the delivery of AOD services or programs when a "successful result" is defined exclusively as a "recovery-based outcome".

. AIVL supports greater investment in appropriate, evidence-based and tailored services for those who are experiencing co-existing mental health and drug dependency issues.

AIVL does not believe it is possible to simply mesh or combine the issues or principles underpinning 'mental health-related recovery' and 'drug use-related recovery' approaches.

AIVL is seriously concerned about the apparent lack of a rigorous, peer-reviewed evidence base and/or an agreed definition to support the 'new recovery' agenda.

AIVL does not believe there is a need to redesign or reorient the current Australian AOD treatment sector towards a 'new recovery' approach.

Instead, AIVL believes we should be focused on reviewing the current AOD treatment system with the view to:

a. retaining those aspects of the system with merit;

b. increasing investment and resourcing levels;

c. improving treatment quality, affordability and flexibility;

d. increasing access to a greater range of evidence-based treatment options;

e. reducing punitive and judgemental treatment approaches;

f. increasing genuine consumer participation and involvement; and

g. improving support for people to identify and achieve their treatment goals and outcomes within a treatment setting that best meets their individual needs.

Annotated bibliography – Published Articles

Title: Impact of Illegality and Criminalisation

Author: AIVL

Publication details

This paper is an excerpt from: Australian Injecting and Illicit Drug Users League (AIVL). (2010). Hepatitis C Models of Access and Service Delivery for People with a History of Injecting Drug Use. AIVL, Canberra.

Hyperlink if available

http://www.aivl.org.au/wp-content/uploads/AIVL-Paper-Impact-of-Illegality-Criminalisation.pdf

Key findings

- Criminalisation is part of the failed attempt to create a "drug free world"
- No discussion of the existing barriers to access and service delivery for people with chronic hepatitis C and a history of injecting drug use would be complete without an examination of the impact of the current drug control laws on health and wellbeing
- There is a need to shift to regulatory models to control drug markets in order to reduce the health and social harms associated with the current drug laws and policies.
- Despite significant thinking and writing on the social determinants of health, there has been comparatively little investigative work into the disproportionate impact of illegality and criminalisation on the health of people with a history of injecting drug use.
- The importance of viewing incarceration among people with a history of injecting drug use as a 'consequence' of illegality and criminalisation is supported by a review of current data in Australian prisons
- It is symbolic violence that underpins the extreme levels of shame experienced by people with a history of injecting drug use and their subsequent willingness to routinely submit to poor treatment and to empathise with those who have power over them.

Recommendations

AIVL believes the illegality and criminalisation associated with injecting drug use is causing unacceptable levels of harm among people with a history of injecting drug use and is acting to create systemic barriers to health equity for this group in the community. For this reason AIVL believes there is an urgent need to commence a process of legislative and policy reform that reviews our entire approach to illicit drugs (and the attitudes that our current approach engenders) in order to improve access and service delivery for people with chronic hepatitis C.

ANNOTATED BIBLIOGRAPHY – PUBLISHED ARTICLES

TITLE: NO ONE WANTS TO USE THE DIRTIES: INJECTING DRUG USERS REFLECT UPON RE-USE PRACTICES

AUTHOR: AIVL

PUBLICATION DETAILS

Duvnjak, A., Morrison, E., Madden, A & Olsen, A. 2015. No one likes using the dirties: A study into the re-use of injecting equipment in Australia. Canberra: Australian Injecting and Illicit Drug Users League

HYPERLINK IF AVAILABLE

http://www.aivl.org.au/wp-content/uploads/No-one-likes-using-the-dirties.pdf

KEY FINDINGS

In 2014 the Annual NSP Survey found that 21% of respondents reported re-use of needles and syringes and ***16% reported receptive sharing of needles and syringes.*** These figures have remained relatively stable over the past 7 years. This is an unacceptably high number that persists despite the existence of needle and syringe programs providing free or low cost equipment to PWID across Australia. The statistics make it clear that more is needed to be done if we wish to reduce high risk injecting practices like sharing.

AIVL was interested in going beyond the statistics to explore, from a drug user's perspective, the reasons why people continue to share injecting equipment.

- 8 focus groups conducted across Australia (NSW, WA, ACT and TAS). Recruited via drug user orgs.
- Total of fifty (50) participants
- Age range: 24-68 years
- Gender mix: 20 women, 28 men, 2 trans
- Main barriers to accessing injecting equipment were reported as:
  - Opening hours and location of NSP
  - Limitations on amount or type of equipment
  - Type of service provided
  - Fear of punishment or repercussions
  - Stigma and discrimination
- None of the participants reported wanting to share equipment. If equipment had been readily available at the time they needed it, they would have preferred to use it.

Recommendations

Further research is required to determine the following:

- The impact of legislation and policy criminalising PWID on access to harm reduction services
- The impact of legislation preventing peer distribution of injecting equipment
- The impact of stigma and discrimination upon PWID and their ability to 'take up' harm reduction messages
- The fear of punitive measures for people on OST and how this impacts upon harm reduction
- Child protection and other services – how fear of punishment may prevent PWID engaging in harm reduction measures

Annotated bibliography – Unpublished Research or Articles

Real People, Real Data (RPRD) – Health Experience Wheel (Consumers Health Forum of Australia (CHF))

Publication details

The 'publication' referenced here is based upon my own personal account of being discriminated against in a hospital setting at a time when I was suffering two life threatening conditions that very nearly left me a paraplegic. The discrimination took place due to my being on pharmacotherapy and perceived as drug seeking when presenting at the emergency department. This account was used by CHF (ACT branch) in the development of the "Real People, Real Data" tool (kit) designed to represent such accounts as a "Health Experience Wheel" graphic. The RPRD tool was developed with a view to providing information about the link between the health services people receive and their health outcomes in a 'graphic' format, outside of the usual statistical measures and patient surveys, so as to better inform healthcare providers and policy makers.

Hyperlink

Whilst there is no hyperlink available to this particular account as such I can provide a digital or hard copy of this material relating directly to my own personal account and the Health Experience Wheel developed from my account if required.

The hyperlink below references the CHF RPRD 'tool kit' for use by those wishing to utilise it to recount and record their own personal experience(s) with the health care system.

https://ourhealth.org.au/content/real-people-real-data-toolkit#.V-Ml5vl97mE

Key findings

The CHF RPRD Health Experience Wheel developed in my case from the version extant in 2014 reflects my experience graphically under four key headings; with each heading highlighting particular aspects of my 'journey' through the health care system via green 'smiley' or red 'sad' emoticons based upon and backed up by the transcribed interview with myself re my experience. The four key headings are as follow:

1) ***Seeking Assistance*** – showed a ratio of 0:1 (positive to negative). "…don't expect you are going to be looked after…every aspect of your care is…in your own hands (and something you will have to fight for)."
2) ***Diagnosis*** – showed a ratio of 2:4 (+ to -); summarised as 'intern stood up to senior doctor to insure care given', 'fear and relief in finally getting a diagnosis', 'could not get diagnosis', 'dismissed due to being on pharmacotherapy', 'sent home without receiving care', '(suffered) severe pain and damage (to spine) due to delay in diagnosis'.
3) ***Treatment*** – showed a ratio of 1:4 (+ to -); summarised as 'eventually got pain relief after nurse noticed level of pain', 'was not given proper pain relief', '(was) not listened to (when requesting pain relief)', '(history as an IV drug user) absolutely played a part in the lack of…a proper regime of pain relief', '(the) lack of support (for me as a patient and person was not properly taken into consideration as a part of a holistic picture regarding my care)'.
4) ***Recovery*** – showed a ratio of 0:1 (+ to -); summarised as '(consideration of my situation following discharge from hospital: my being in a steel back brace, with walking stick, and remaining in care as an outpatient for six months, with no take away pharmacotherapy allowed – hence obliging me to travel by public transport to dose was entirely) contra to any notion of (proper and adequate) health care (and was actually harmful bordering on dangerous).'

RECOMMENDATIONS

There were no recommendations as such made based upon this work, rather it has been used in the development of the RPRD tool-kit as a means by which the Consumers Health Forum of Australia can further partner with consumers and identify those areas in the current health care system that may require change. This is being done with a view to subsequently advocating on the behalf of health care consumers with policy makers so that they in turn may be better informed when undertaking strategic decisions about health policy, services and spending.

In my case the Health Experience Wheel reflected, based on the transcript of interview, a profound degree of stigma driven discrimination patently demonstrated in both the dismissal of my initial concerns leading to a much greater degree of harm that would have been the case had I not been dismissed in the first instance as ‘drug seeking’ based solely upon my status as a pharmacotherapy client and past IV drug user.

INITIATIVES TO ADDRESS STIGMA AND DISCRIMINATION

PEER BASED ORGANISATIONS FOR PEOPLE WHO USE DRUGS

Author if Different from your Agency: AIVL and our member organisations

Health Services with whom this is Delivered/Run

Various

Dates/times

Various

Hyperlink

http://www.aivl.org.au/member-organisations/

Evaluation of the Resource/Training Program

Annual Report http://www.aivl.org.au/wp-content/uploads/AIVL-2015-Annual-Report.pdf

Could this resource be further developed or rolled out?

Currently there are funded peer based organisations for people who use drugs but these are not consistent throughout all states and territories.

Just like AIDS Councils and sex worker organisations, peer based organisations for people who use drugs, by their very existence demonstrate that people who use drugs are valuable, they are part of the community, can contribute to solutions and their lived experience is actually specialist knowledge that allows the staff at peer based orgs to do their work. In this way, this reversal of much of the shame and negative attitudes towards drugs use, effectively making them anti-stigma initiatives.

Discrimination Know Your Rights Survey (AIVL and our member organisations)

Health Services with whom this is Delivered/Run

None. This survey is targeted towards our own community, providing an opportunity for people who use drugs a platform by which they can tell us about the discrimination they have experienced.

This data is then used to inform AIVL's understanding of current community experiences of discrimination

Dates/times

Current and ongoing

Hyperlink if available

http://www.aivl.org.au/stories/online-notification-form-for-discriminatory-action/

Evaluation of the Resource/Training Program

http://www.aivl.org.au/wp-content/uploads/20151008_Report-Web.pdf

Could this resource be further developed or rolled out?

This is an unfunded intitiative implemented by AIVL. The potential to expand and promote this survey would require appropriate funding and support in order to be realised.

'Putting Together the Puzzle' Stigma, Discrimination and Injecting drug use.

TRAINING MODULE FOR HEALTH CARE PROFESSIONALS AND STUDENTS (AIVL)

Health Services with whom this is Delivered/Run:

All health services that request training, including community health, GPs, alcohol and drugs services, and social welfare services

Health Care professionals and students

Dates/times

from 2015-2016

Hyperlink if available

http://www.health.nsw.gov.au/hepatitis/Pages/injecting-drug-use-elearning.aspx

Evaluation of the Resource/Training Program

The evaluation of the Module has been successful both in terms of anecdotal reports from our groups but also the numbers of organisations who have requested to use it after participating.

Could this resource be further developed or rolled out?

Yes – the module has been developed into an online training Module for HETI in NSW and AIVL is currently exploring options for a more widely available online version of the module.

Contact Details for Author or Person Responsible for Submission

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