Impact of Stigma & Discrimination

(This paper is an excerpt from the recently published AIVL Hepatitis C Models of Access & Service Delivery for People with a History of Injecting Drug Use which outlines some of AIVL’s current thinking and some of the key evidence supporting the need for drug law reform. It should be read in conjunction with the associated papers on Harmonising Drug Control Laws & Policies with Public Health Approaches, Enshrining a Human Rights Framework, Social, Cultural, Legal & Economic Determinants of Health and the Impact of Illegality & Criminalisation.)

Erving Goffman’s work on theorising stigma describes stigma as “an attribute, behaviour, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one.” Goffman goes further to define stigma as a “special kind of gap between virtual social identity and actual social identity”. Virtual social identity is the assumed characteristics and attributes we transpose onto people when we first meet them whereas actual social identity is the characteristics and attributes someone is proved to possess which may be quite different to our assumptions about a person (Goffman, 1986). In this way, Goffman suggests that stigma acts to “spoil normal identity” and reduce people from being a whole and usual person to being a tainted and discounted one (Goffman, 1986).

It is not difficult to understand how the stigma and discrimination routinely experienced by people with a history of injecting drug use can profoundly affect people’s health status and make them extremely vulnerable to poor health. Research with injecting drug users has demonstrated the links between policy and practice and community and societal attitudes towards injecting drug users and the subsequent negative implications for IDU health. (Tindal, 2010) The shame and stigma associated with injecting illicit drugs forces people away from information, support and services and isolates them from family, friends, crucial health and social services and the rest of society. For many people with a history of injecting drug use, the long-term effects of being locked outside of mainstream society are; serious health problems, poverty, unemployment, poor levels of education, family and community breakdown and in many cases, premature death. Further, stigma has been directly associated in research with high-risk injecting practices resulting in HIV and hepatitis C infection, high levels of drug dependence, repeated incarceration, severe economic disadvantage and homelessness (Southgate, 2003).

There is an inextricable link between injecting drug use related stigma and discrimination and hepatitis C related discrimination. Both the NSW Anti-Discrimination Board Inquiry into Hepatitis C Related Discrimination in 2001 and the Senate Community Affairs Reference Committee on Hepatitis C and the Blood Supply in Australia in 2004, found that hepatitis C is a highly stigmatised condition, that hepatitis C discrimination is rife and that discrimination in relation to injecting drug use lies at the heart of both of these situations (NSW ADB, 2001). Indeed the NSW Anti-Discrimination Board Inquiry concluded that strategies designed to address discrimination against people on the basis of their past, current or assumed drug use must be an integral part of responding to hepatitis C related discrimination.”
The C-Change Report undertaken by the NSW Anti-Discrimination Board in 2001 was at the time, and remains now, the most comprehensive examination of issues relating to stigma and discrimination among those most affected by hepatitis C in Australia. Further work on this issue was also conducted in the 3D Project – Diagnosis, Disclosure, Discrimination & Living with Hepatitis C published in 2003 (Hopwood and Treloar, 2003). Included in the recommendations and conclusions of the C Change Report are the following points:

- **Hepatitis C is a highly stigmatised condition and... discrimination against people with hepatitis C is rife.**
- **Health care settings were the most commonly reported context for hepatitis C discrimination.**
- **Discrimination often has a profound impact on the lives of people with hepatitis C; it frequently has damaging health, financial, social and emotional consequences both for people living with hepatitis C and the community. The experience of discrimination acts as a deterrent to people accessing the health system, with all the consequences this brings for the health of people with hepatitis C and the community.**
- **The fear of stigma and discrimination can lead people who believe they might already have contracted hepatitis C, to be reluctant to seek testing and treatment for hepatitis C.**
- **Societies have shown a distressing record of treating people with particular diseases as outcasts and denying them fundamental human dignity (NSW ADB, 2001).**

Findings from the 3D Project Report include:

- 27.8% reported experiencing discrimination from a health care worker other than a doctor;
- 12.9% experienced discrimination from a doctor;
- 12.7% reported being refused medical treatment due to hepatitis C status;
- 45% said discrimination had negatively affected their emotional health; and
- 35.7% said their physical health had been negatively affected by discrimination (Hopwood and Treloar, 2003).

A conclusion reached by the 3D Project was that “hepatitis C related discrimination occurs in a variety of social domains and is especially salient for people identified as, or assumed to be, injecting drug users” (Hopwood and Treloar, 2003). A paper delivered to the 5th Australasian Viral Hepatitis Conference (Sydney 2006) by Daniel Tarantola stated that:

“**Discriminatory actions do not only amount to violations of human rights, but also to unsound public health practice as they act as a deterrent to access early diagnosis, support and prevention and treatment services**” (Tarantola, 2006).

And mentions:

“**...the nefarious effects hepatitis C markers can have on people’s access to care and other health and social services and, as importantly, on human health, welfare and dignity**” (Tarantola, 2006).

Unfortunately, in the many years since the C-Change and 3-D reports were published there has been little specific work done to address the issues identified or the recommendations made. This is of particular concern because the C-Change Report highlighted the systemic and entrenched nature of the problem across all levels of society but in particular in healthcare settings, employment, the criminal justice system and the general community including the media (NSW ADB, 2001). The impact of stigma and discrimination on the health and lives of people with a history of injecting drug use is significant. Although research in this area is limited, on the
occasions they have been asked, people with a history of injecting drug use routinely identify stigma, discrimination and fear of poor treatment by health system as the main reasons they do not access primary health and other services including hepatitis C clinical services (Aitkin, 2002). In the Barriers and Incentives to Drug Treatment for Illicit Drug Users National Research Project more than half the participants reported that they had been discriminated against by family (63%), staff at pharmacies (63%), friends (62%), doctors/nurses (54%) and a significant number mentioned discrimination by partners (37%), other health workers (36%), landlords (36%) and workmates (34%) (Treloar, 2004). So widespread is the problem of drug use-related stigma and discrimination, that anecdotal reports indicate that many individual drug users live with extremely painful, debilitating and even life-threatening conditions rather than seeking out treatment from health services including hepatitis C prevention, diagnosis and treatment services.

Indigenous drug users, drug users from CALD backgrounds and drugs users with mental health issues are among the groups that live with multiple layers of stigma, discrimination and human rights violations. Poor attitudes among service providers, the media and the general community towards these groups results in increased vulnerabilities and levels of social exclusion including significantly higher rates of homelessness, incarceration, unemployment, poverty, social isolation and chronic health problems. (DoHA, 2005). Indeed, research shows that rates of hepatitis C infection are between 3 and 13 times higher among Indigenous people with a history of injecting drug use than their non-Indigenous peers with variations between jurisdictions and age groups (NCHECR, 2009a).

The National Hepatitis C Strategy specifically highlights poor access to mainstream services as one of the main barriers to effectively addressing hepatitis C related issues among Aboriginal and Torres Strait Islander people (DoHA, 2010). The National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy 2010-2013 also identifies a number of factors that place Aboriginal and Torres Strait Islander people who inject drugs at risk of hepatitis C including a lack of access to culturally appropriate services, discrimination and stigmatisation, concerns about confidentiality in service provision and a lack of support to address BBV issues in the broader context of their health and lives (DoHA, 2010b).

Indigenous people who inject drugs have been identified by AIVL and the relevant nationals strategies as needing specific and priority focus to address the disproportionate affect BBVs are having on this group of people within our community. Higher morbidity and mortality rates, poorer access to health and social services and supports and much greater incarceration rates all suggest that hepatitis C is likely to have a significantly higher impact on Indigenous Australians with a history of injecting drug use. There is an urgent need to address the impact of high levels of stigma and discrimination on Indigenous drug users which underpins the higher burden of disease among this group.

There is also a significant need to address disproportionate rates of hepatitis C and other BBVs among people with a history of injecting drug use who are of Asian cultural background. Research with this group has shown higher rates of infection and increased risk of transmission associated with Asian ethnicity, recent incarceration, public injecting and duration of injecting (Maher, 2004). These findings suggest there is a need not only for increased peer education/support for and by Asian people with a history of injecting drug use but also an urgent need for systemic change that seeks to increase access to health services including reducing barriers caused by stigma and discrimination and developing alternatives to incarceration.
The National Hepatitis C Strategy 2010-2013 has identified “minimising the personal and social impact of hepatitis C” as one of three overarching goals for the life of the Strategy. The main objective of this goal is to “reduce hepatitis C related stigma and discrimination in health care settings” (DoHA, 2010). Further, the Strategy also acknowledges that the social ramifications of hepatitis C infection particularly the stigma and discrimination associated with hepatitis C and the barriers it creates to individuals accessing prevention education, care, support and treatment, underpins all activities within the Strategy (DoHA, 2010).

A market research report recently commissioned by AIVL reinforces the fact that discrimination against people with a history of injecting drug use is widespread and, in many cases, deemed acceptable by people without a history of injecting drug use. The market research found that “many participants from the general public believe that marginalising people who inject drugs is positive for society as a whole...” and many openly admitted to discriminating against people who inject drugs. Essentially, stigma and discrimination toward people who inject drugs is perceived to be a useful prevention strategy among a large portion of the general public participating in the focus groups. It was seen as a means of controlling the problem and importantly, the general public in the focus groups did not identify stigma and discrimination towards injecting drug users as inappropriate. It is also worth noting that discrimination was on the basis of both actual and presumed injecting drug use and members of the general public admitted to having little or no actual contact with people who inject drugs (Parr, 2010).

Negative attitudes towards people with a history of injecting drug use were not limited to the general community:

- Younger respondents in the medical professionals group tended to believe that a stigma should exist for people who inject drugs;
- Some medical professionals tended to have the same views [as the general community] in regards to a physical stereotype about people who inject drugs; and
- In the current social and legal environment, the general public and many medical professionals feel that stigma and discrimination toward people who inject drugs is an important means of containing the practice and should exist (Parr, 2010).

While AIVL is not at all naive about the significant challenges that we are seeking to take on in tackling the issues identified through the market research, we equally do not feel that we have an option in relation to ‘whether’ as a sector or community we try to take those next steps or not. From the perspective of halting the transmission of hepatitis C and reducing barriers to prevention and treatment access, to do nothing, even if the challenges are significant, is not an acceptable option either for those most affected by hepatitis C or for the community as a whole. This is also supported by the Anti-Discrimination Board of NSW that stated:

“Protection of the human rights of people with hepatitis C, and those most at risk of infection, particularly people who inject illicit drugs, is critical to an effective response to hepatitis C” (NSW ADB, 2001).

AIVL believes that until we address some of the fundamental issues that underpin IDU related stigma and discrimination we will continue to see people with a history of injecting drug use disproportionately affected by preventable diseases, experiencing unnecessary levels of drug related harm and routinely dealing with unacceptable barriers to treatment and basic health and social services. This is supported by research into the theory of stigma and discrimination and the experiences of injecting drug users in Australia which concluded that:
“... redressing the negative effects of stigma requires political will, financial support, increased community commitment and a better understanding of the links between the social determinants of health and the poor health status of injecting drug users. Without reducing stigma of injecting drug users the health of this marginalised population is likely to get worse, which will have broader negative population health effects” (Tindal, 2010).

As the issues above highlight, actual and assumed injecting drug use behaviour underpins the vast majority of hepatitis C related stigma and discrimination. It is also clear from the market research that the majority of discrimination towards people who inject drugs (and therefore those most affected by hepatitis C) is driven by stereotypes, misinformation and a process of dehumanising drug users particularly through the media. The question remains however, what is at the basis of the attitudes and values that lead to these dehumanising levels of stigma and discrimination against people with a history of injecting drug use? We have already identified that when it comes to understanding the drivers of poor health and vulnerability among people with a history of injecting drug use it is necessary to move beyond the concept of the social determinants of health and to consider the impact of structural violence - the systematic ways in which social structures and institutions can harm and exclude people. But what explains the willingness of many in society to view such treatment of people with a history of injecting drug use as acceptable and even actively encourage it? To answer this it is necessary to consider a further question “is there a structural driver of stigma and discrimination against people with a history of injecting drug use?” (To answer the above question, please see the paper on the Impact of Illegality & Criminalisation.)

Details of references used in this paper can be found in the ‘References’ section of the AIVL Hepatitis C Models of Access & Service Delivery for People with a History of Injecting Drug Use from which this paper is an excerpt.