

# **An epidemic of difference: A social analysis of hepatitis C-related discrimination**

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## **A. Introduction**

In November 2000, the President of the Anti-Discrimination Board of New South Wales (ADB), Mr Chris Puplick, announced a State-wide enquiry into hepatitis C-related discrimination. The Enquiry was launched in Sydney on March 15<sup>th</sup> 2001, with hearings conducted in Wollongong, Goulburn, Dubbo, Lismore and Newcastle throughout May 2001. Sydney hearings were held in June and August 2001. In addition to public hearings, the ADB invited written submissions from individuals and organisations.

The National Centre in HIV Social Research (NCHSR) was invited to assist in the analysis of submissions tendered to the ADB's Enquiry into Hepatitis C-related Discrimination by providing a sociological analysis of the central themes as they appear in both the written and oral submissions.

## **B. Background to the hepatitis C epidemic in Australia**

Prevalence studies of the hepatitis C virus in Australia place the number of people infected at between 130,000 and 234,000 (Law 1999; National Centre in HIV Epidemiology and Clinical Research 1998), approximately 90,000 of whom reside in NSW. Currently, hepatitis C is the most frequently reported notifiable infection in Australia (National Centre in HIV Epidemiology and Clinical Research 2000). Research indicates that the majority of people contract hepatitis C through sharing contaminated injecting drug use equipment (Crofts et al. 1993; Crofts et al. 1997; Freeman et al. 2000; Macdonald et al. 1996). Australia has an incidence of around 10,000 new hepatitis C infections annually with about 91% of new infections occurring among injecting drug users (Dore et al. 1996). Approximately 10% of all hepatitis C infections in Australia are the result of blood transfusions or the use of blood products prior to 1990 when screening was introduced (Hepatitis C Council of New South Wales 2000).

The combination of a significant pool of infected people and the long duration of illness associated with hepatitis C infection indicates that the overall health and economic costs to Australian society in the years ahead will be substantial (Wodak 1997). The growing public health significance of the epidemic is evidenced by the implementation of the National Hepatitis C Strategy 1999-2000 to 2003-2004, an initiative aimed at promoting and supporting treatment measures, support and care (Commonwealth Department of Health and Aged Care 2000).

The current epidemic of hepatitis C is often likened to that of HIV/AIDS, where specific populations and practices are linked to risks of infection. In Australia, HIV is commonly transmitted via unprotected anal intercourse and principally affects gay men living in highly visible and geographically focused urban gay communities. In Australia, hepatitis C is an epidemic that predominantly affects people who practice, or have practiced, injecting drug use. However, people who contracted hepatitis C from

injecting drug use do not constitute a 'community' in the same sense as the gay community (Hulse 1997) and a tendency to liken this current epidemic with HIV/AIDS may obscure significant disparities.

Hepatitis C is an 'epidemic of difference'<sup>1</sup>. People who contracted hepatitis C from injecting drug use come from a broad range of backgrounds and include people who experimented with injecting decades before discovering their infection. Some of these people may have only injected once or twice, while others are current injectors, including those who are drug dependent. People who have ever injected in their life do not comprise a homogeneous group: they inhabit corporate boardrooms, the suburban family home, and the local football club, as well as park benches.

In addition, a significant minority of Australians contracted hepatitis C via non-injecting means, such as medical procedures, tattooing, skin-piercing, accidental household and workplace transmissions, or following mass vaccination programmes in their country of birth. Evidently, people with hepatitis C are culturally and geographically diverse and perform a variety of social roles, which makes this epidemic, from a socio-cultural perspective, unique, multi-faceted and extremely complex. These differences affect the way people cope with hepatitis C infection, how they experience hepatitis C-related discrimination, and their power to respond to stigmatisation and discrimination. The following section defines discrimination and stigma and discusses these constructs in relation to social identity theory, a tool useful for understanding the processes involved in discrimination of people with non-normative values and lifestyle practices, and those living with a stigmatised chronic illness. This discussion provides a theoretical framework from which to view evidence tendered to the Enquiry.

### **C. Discrimination and stigma**

Discrimination refers to "actions or practices that are carried out by members of dominant groups, or their representatives, which have a differential and negative impact on members of subordinate groups" (Feagin et al. 1978: 20-21). There are two major approaches to thinking about discrimination: the first involves the prejudice-causes-discrimination model which perceives discrimination as individualistic, overt, sporadic and episodic and presumes that individuals' attitudes and behaviour are causally linked. This approach focuses on individuals or small groups and their intentions and while valid in many contexts, this conceptualization of discrimination has been critiqued for its assumption that attitudes and behaviour are always consistent (Merton 1970). Another approach to discrimination looks beyond personal rationalizations and motivations to social structures where discrimination is perceived to be overt or covert, routine and continual. This approach focuses on institutions and organisations where discrimination can be either intentional or unintentional (Feagin et al. 1978; Herdman et al. 1995; Henriques et al.1984). It is useful to consider both approaches when thinking of discrimination.

Discrimination is associated with, and the enactment of, stigma. Stigma is a term used to 'refer to an attribute that is deeply discrediting' and a stigmatised person is someone who embodies 'an undesired difference' (Goffman 1968 p. 3). Social groups stigmatise

individuals or groups of people who display difference from social norms and who identify with or enact behaviours that hegemonic groups consider deviant.

<sup>1</sup> Courtesy of Dr Erica Southgate.

Stigmatisation is manifested through rules and sanctions directed towards affected people (Malcolm et al. 1998). It is a means by which communities defend against overt threats to cultural values and social control can be maintained through marginalizing those people who exhibit particular traits (Malcolm et al. 1998; Gilmore et al. 1994). Stigmatisation involves the labeling of people as lacking conformity with the salient values enshrined within a culture, and the kind of behaviours that come to be stigmatised can vary widely between cultures (Fulton 1999; Pittam 2000). The stigmatizing trait or value is often one that conflicts with an important cultural value that is being upheld by the majority in a community. By marginalizing certain groups and individuals, societies articulate important community values and define boundaries of accepted behaviours (Gilmore et al. 1994).

The burden of stigma often weighs heaviest on the poorest and most marginalised people in our community and this point reveals the political dimension of stigma, that is, powerful groups can enforce rules onto less powerful groups (Fulton 1999). The following explains the nature of social divisions as posited by social identity theory and discusses the categorisation of people with stigmatised diseases into social out-groups.

### *CI. Social identity*

**‘If history teaches us anything at all, it teaches us that human beings have a powerful need to form groups and that the sacrificial victimization of scapegoats is often an indispensable ingredient for maintaining social cohesion among the members of such groups.’** (Szasz 1987, in Gilmore et al. 1994 p. 1346)

Here, Szasz discusses the scapegoating of drug users within modern American society. People who represent difference to the majority in their values and beliefs and/or practices are often stigmatised, stereotyped and scapegoated as a means of preserving the safety and validity of the hegemonic group and the integrity of individuals who claim membership.

Social identity provides a theoretical framework to explain the propensity of people to stigmatise and stereotype, often erroneously (Henriques 1984), and to simplify and divide the world into the ‘us’ and ‘them’ binary. Specifically, social identity theory involves three basic assumptions: people categorize others into in-groups and out-groups; people are motivated to strive for a positive self-concept and gain a sense of self-esteem by identifying with a particular in-group; and people’s self-concept partly depends on how they evaluate their in-group compared with other groups (Sears, Peplau and Taylor, 1991). This theory describes people’s desire to belong to a ‘superior’ group, and to claim the psychological, social and material benefits obtained from such membership. By identifying with, for example, specific religious and socio-political groups, in-group norms, values and beliefs provide a structure from which individuals view the ‘other’.

Apart from the stigmatizing of specific behaviours and values, people experiencing illness may also be subject to stigmatisation (Lupton 1994c). Some diseases have a history of eliciting stigma and sick people are often labeled and excluded from a range of social contexts. Some diseases are perceived as a threat to the self or one's community. For example, people with a sexually transmitted infection (STI) or mental illness are at times stigmatised and may suffer discrimination as a result. Those affected are labeled as belonging to an out-group. This is seen as a method of preserving the physical and moral health of the community against the problems represented by the disease (Gilmore et al. 1994). When people with an STI are stigmatised, for example, the disease comes to represent all the 'suffering and evil' in society and people with the disease are positioned as an out-group representing 'societal shortcomings, inadequacies, unmet needs, or unrealized expectations' (Gilmore et al. 1994 p. 1346). People with a STI (or those presumed to have a STI) are judged, scapegoated and blamed by others for their own disease state as well as a range of other problems that exist among society.

HIV/AIDS has become one of the most stigmatised diseases of recent times and is characterized as a multiple epidemic, that is a viral epidemic as well as an epidemic of stigmatisation, scapegoating and discrimination (Gilmore et al. 1994). The early days of the epidemic saw calls from both individuals and some social institutions for people living with HIV/AIDS to be quarantined, to be excluded from participating in the work force and other social contexts, and to be identified as carriers of death and disease (Sontag 1989; Crimp 1987). These actions were aimed at maintaining a distance between the healthy, 'moral' majority and the threat of disease that was seen as a result of a deviant lifestyle and practices of a minority. Stigmatisation aimed to simultaneously identify and disempower those affected by HIV/AIDS and preserve hegemonic values.

The stigmatizing, scapegoating and discrimination familiar to many people living with HIV/AIDS, has in some ways being replayed over the past decade, this time in the context of hepatitis C. If a condition is understood to be the result of an individual's own actions, then those affected are likely to be viewed adversely and discriminated against (Jones et al. 1984). Whereas gay men's sexual practice was construed to present a major threat to the preservation of social order during the HIV/AIDS epidemic, the stigmatised villains and 'guilty' victims of the hepatitis C epidemic are injecting drug users.

### *C2. Fear of contagion and 'userphobia'*

Discrimination against people living with an infectious disease is often based on both rational and irrational fears of contagion (Kippax et al. 1991). Rational fears concern chronic illness and disease that results from infection with a transmissible virus. Irrational fears reflect exaggerated estimates of risk of contagion. These fears often lead people to avoid social interaction with those known or assumed to be infected and may lead to discrimination against people associated with risk groups and practices. Perceptions of risk are highly subjective. Individuals do not usually assess risk from an exclusively scientific standpoint, but in terms of personal and cultural values and beliefs (Kippax et al. 1991).

**‘The panic and uncertainty that accompany epidemic disease may lead to a desperate search for explanations ... Stigmatization seems to provide a partial (although spurious) answer ... the convenience of having an already despised or suspect group in the vicinity allows for quick attribution of causality and blame.’**

(Turner et al. 1989, p. 391)

Because of the way society views illicit drug use and injecting drug users, people are socialized to hold certain beliefs about users and come to question, for example, their value as members of society, their ability to find and maintain employment, and their capacity to form relationships with family and others (Fulton 1999). Injecting drug users are assumed to be addicted and to have close ties with crime in order to finance their addiction. People who use drugs are often stereotyped as lacking social worth and a danger to the community because they are likely to spread their negative characteristics to others. This seems especially true if the user comes from a poor socio-economic background and injects heroin (Acker 1993; Jones et al. 1984; Fulton 1999).

‘Userphobia’, a term loosely defined as a fear and dislike of injecting drug users, describes a palpable distaste for anyone admitting to, or associated with, injecting. This loathing may be interpersonal and aimed at individual users, or systemic and focused on organisations such as methadone clinics and needle and syringe programmes. Some individuals may be more userphobic than others. Userphobia informs many of the prejudicial beliefs and discriminatory practices leveled at people with hepatitis C by various sections of the community. At the core of userphobia is the division of people into ‘guilty’ and ‘innocent’ victims of hepatitis C. This division is apparent when people who acquired their infection through injecting drug use are held responsible for their own disease. Conversely, those people who contracted hepatitis C through non-injecting means are seen as the ‘innocent’ victims of the epidemic and not held responsible for their infection. A ‘guilty’ finding may be used to justify discriminatory treatment of an individual with hepatitis C infection.

Social identity theory is useful in understanding how people living with hepatitis C come to be positioned as belonging to an out-group. There is a strong association between injecting drug use and hepatitis C in the media, the minds of the general public and among social institutions like the health care system. Illicit drug use is one of the most stigmatised behaviours throughout the world, and users belong to some of the most marginalised populations that are often scapegoated and discriminated against (Gilmore 1996). In a society that emphasises rationality and values sobriety (Marr 1999; van Ree 1997), non-users may view illicit drug use as evidence for a moral, personal and/or biological inadequacy in those who ‘choose’ to use (Gilmore 1996). Additionally, because of the illegal status, drug users are positioned as criminals flouting the rules of society. If participation in an illegal activity is also synonymous with the transmission of blood borne viruses and other negative health outcomes, including a compromising of human rationality (van Ree 1997), social identity theory suggests that those whom eschew these activities will act to distance themselves from people involved in order to preserve in-group safety and uphold in-group values. Boundaries are created to delineate the in-group containing rational, healthy, law-abiding citizens and those deviant ‘others’ who compromise their mental and physical health by choosing to use illicit drugs. Boundaries reaffirm hegemonic social values (ie. observation of the law and the prioritising of one’s health) by excluding deviant

ones (Gilmore et al. 1994), satisfies the in-group's need for security, and bolsters a collective self-concept and sense of esteem.

Recent responses to epidemic disease are often characterised by processes of stigmatisation and discrimination that further endanger the health of affected people (Kippax et al. 1991; Herdman & Kippax 1995). When the community and media think of people living with hepatitis C, there is a strong tendency to focus on the practice of injecting drug use as the cause of their infection. Indeed, for many, hepatitis C and injecting drug use have become synonymous.

#### **D. Method**

The Anti-Discrimination Board sought input to the Enquiry from a broad range of community-based organizations, Area Health Services, relevant government departments, experts in the field, private sector institutions and individuals (see Section 1.3 – 'Methodology' in the main report for a detailed account of the procedures used for collecting evidence). The Enquiry was advertised widely in the print and electronic media, and via two broadly distributed information fact sheets produced by the ADB and Hepatitis C Council of NSW. In response, oral and written submissions were received from a variety of individuals and organizations throughout Sydney and regional NSW. On receipt of a written submission, the ADB returned a letter of acknowledgment detailing the role of the NCHSR in the Enquiry. A two-week period was granted for people making written submissions to withdraw consent for their evidence to be used in the NCHSR analysis.

In total, one hundred and ten written submissions were received by the ADB. Eighty-two of these became a primary source of data for use in the NCHSR analysis. In addition, the author attended nine out of thirteen oral hearings held throughout New South Wales. Extensive notes were taken from both data sets (ie oral and written submissions). The submissions were analysed using a grounded theory approach (Glaser and Strauss 1970). The frequency with which preliminary concepts occurred was recorded, enabling the identification of emerging clusters of themes. The theoretical framework of stigma and social identity was used to interpret the findings. The analysis describes themes within the submissions that emerge as significant or important to individuals.

##### *D1. Submissions from the health care sector*

A high proportion of submissions received by the Enquiry concerned health care workers. The methods of data collection may have influenced the extent of this evidence received by the Enquiry. The Enquiry was advertised among health care settings such as community health centers, needle and syringe programmes, methadone clinics and other key health services. These settings provide a significant path to accessing people with hepatitis C and workers in the field who had information and direct experience of discrimination. The high proportion of submissions relating to discrimination from health care workers, to a certain extent, reflects the use of this avenue for advertising the Enquiry. Additionally, this evidence reflects the probability that people living with hepatitis C are more likely to disclose their hepatitis C infection in health care settings than in other community contexts. Therefore, health care is a key

environment in which hepatitis C-related discrimination is likely to be enacted. Many instances of hepatitis C-related discrimination used in this report are taken from the health care sector as submissions pertaining to this context provided the most salient examples.

The following sections discuss the major themes that emerge as informing hepatitis C-related discrimination, beginning with: misinformation pertaining to hepatitis C infection; the confounding of injecting drug use and hepatitis C; and evidence of userphobia.

### **E. Misinformation and the confounding of hepatitis C and injecting drug use**

A submission to the Enquiry from the Hepatitis C Council of New South Wales (HCC of NSW) reported that hepatitis C-related discrimination occurs either because of ‘a non-rational fear of infection’ or the virus’ association with injecting drug use and suggests that it is often hard to tell which is driving discrimination. Poor knowledge of hepatitis C infection among the general community, including the health care sector, was a major finding of the Enquiry. Many people confuse the hepatitises. A hepatitis C educator stated that there ‘is a considerable amount of misinformation’ concerning the virus within the community. Poor knowledge of the hepatitis C virus was reported among a variety of workplaces, such as insurance companies, funeral services and schools and among some health care workers, including general practitioners.

Submissions to the Enquiry highlighted how ignorance of hepatitis C appeared to underpin some of the negative attitudes and discriminatory practices that people encountered. A quote from a woman who attended a social gathering with friends, where the topic of discussion was hepatitis C and HIV/AIDS, highlights a positive person’s reaction to community ignorance of the virus:

**‘[I was] shocked at the attitudes of some of the people ... I would not have told them that I had hep C or they would have stoned me, that’s how they came across to me’.**

Ignorance and fear of the virus may explain why some people are excluded from participating in activities within their social networks when there is no risk to others, and why infection control procedures are sometimes implemented in inappropriate contexts.

Evidence was also tendered to the Enquiry suggesting hepatitis C-related discrimination was inextricably linked to discrimination of injecting drug users. The association of hepatitis C infection with injecting drug use has been reinforced by the media and appears to be so significant that in the minds of many health care workers, and indeed members of the public, hepatitis C and injecting drug use have become indistinguishable. According to one service provider:

**‘People are automatically assumed to be current users when they disclose their [hepatitis C] positive status to health care workers.’**

The confounding of hepatitis C and injecting drug use reportedly underpins many instances of hepatitis C-related discrimination. Service providers and individuals claimed that hepatitis C-related discrimination, especially in health care settings, is informed by userphobia. According to a submission from a user, in the context of health care, either a disclosure of injecting drug use or a hepatitis C positive sero-status may result in poor treatment:

**‘Once they [health care workers] find out you have hep C or are an addict, they treat you like shit.’**

Some health service providers claimed that there is a cultural norm of discrimination against injecting drug users existing among the health care system. Individuals and service providers maintain that some health care workers find it difficult to have positive attitudes towards injecting drug users. An ex nurse stated:

**‘Some nurses practice punitive measures when they identify patients as being ex or current users.’**

Injecting drug use is a stigmatised practice and userphobia positions injecting drug users as an out-group with irrational values, needs and lifestyle practices foreign to those of mainstream society, as well as being considered a contagious threat to the health of the majority. Health workers were said to perpetuate values and beliefs that were ‘unhelpful’ to users and by association, people with hepatitis C. Many health care workers were reported to view illicit drug use as a criminal rather than a public health issue. Manifestations of discrimination are varied, however, one example given by workers from methadone clinics and needle and syringe outlets claimed that pain relief is difficult to get if the health care worker thinks that the patient is a user who is just ‘shopping for Pethidine’. Some general practitioners and nurses were described as openly hostile to users and often dismissive in their treatment of users.

According to a methadone clinic worker, the label ‘scum-bag junkies’ is often applied to users in health care settings. Many non-users see illicit drug use as an ‘evil’ pursuit that stems from a moral and personal inadequacy whereby users cannot, or will not, resist taking drugs (Gilmore 1996). This socially pervasive interpretation positions drug users as self-indulgent, weak-willed and criminal. Health care workers’ negative attitudes to drug users may be based on issues of morality and health, and reinforced on the grounds that injecting drug use is an illegal activity. A quote from a woman on a methadone maintenance programme highlights the poor attitudes and treatment leveled at injecting drug users by some health care workers:

**‘I present as a nice North Shore mum, but when I go to the methadone clinic .... staff are rude, unhelpful, badly informed, and their treatment of people who can’t fight back is contemptible. They make fun of their clients, comment on their clothes and mental condition and generally act like they are infinitely superior. This is a private clinic. What the hell happens at public ones?’**

The stigmatisation and concomitant aggressive dislike of injecting drug users was so common in health settings that some service providers believed that injecting drug users only go to see a doctor ‘when they absolutely must’, and that they expected to

experience discrimination from general practitioners and other health care workers. Individuals and service providers suggested that this self-limiting behaviour by users reduces the incidence of user-related discrimination, and contributes to an under-estimation of the severity of discrimination.

The fear and dislike of injecting drug users and ignorance about hepatitis C infection appears to be widespread. The equation of infection and injecting drug use can be regarded as so pervasive among the general community that it affects all. In the words of one user:

**‘People are ... scared of you being a drug user ... because straightaway you’re likely to have everything.’**

## **F. Themes of Stigma and Practice of Discrimination**

### *F1. Disclosure*

Disclosure emerged as a major theme in the Enquiry, and in the context of health care settings disclosure often resulted in a range of negative outcomes for people. People commented on ‘a change’ or ‘a shift’ that occurs among some health care workers following disclosure of hepatitis C sero-status. A submission from a user organisation states:

**‘When you disclose your status [to a health care worker], you see a shift and they treat you differently, but what can you do about that?’**

Similarly, a man believes he is doing the right thing by disclosing to health care workers, however, when he does he notices that:

**‘ ... the atmosphere changes, you know their body language changes and the way they sit back as if to put distance between themselves and me.’**

These experiences have caused these patients to rethink their habit of disclosing as they believe their interactions with health care workers would be less stressful if they did not disclose.

Reaction to disclosure of hepatitis C infection was not always so subtle. Often health care workers were reported to behave in a patronising and abusive manner, assuming infection occurred through injecting drug use regardless of patients’ accounts. For example, when a patient with medically acquired hepatitis C objected to his doctor’s assumption that his infection was the result of injecting drug use, his doctor retorted:

**‘ ... all you junkies are liars.’**

Service providers supported observations by individuals that following a disclosure, health care workers often assume a history of injecting. These assumptions also occur in workplace contexts. Employees tell of their experiences with co-workers and employers following workplace disclosures of hepatitis C. Often rumours circulate throughout the work environment that position sero-positive people as ‘heroin addicts’

and these may be accompanied by innuendo regarding their sex life. Similarly, positive people were sometimes marginalised or completely excluded from friendship networks, rumours were circulated about their sexual practices and drug use, families behaved differently with loved ones, and relationships became very tense or completely broke-down. One woman wrote despairingly of the effects of disclosure on her relationship:

**‘My husband of fourteen years never has sex with me now, and has lost all loving feelings towards me. I am a loving person and give love and need love [and] that has hurt ...’**

Finally, disclosing a hepatitis C positive status to organisations like insurance companies and banks often resulted in poor outcomes for people. Life insurance policies and mortgage insurance were reportedly denied to those who had disclosed their positive sero-status. These outcomes exemplify a cross-section of people’s reactions to the disclosure of an infection associated with a stigmatised practice.

Scambler and Hopkins (1986) discuss two different ways that people experience stigma. ‘Felt’ stigma involves the perceptions that people have about their own condition and the ways that others respond to this, and ‘enacted’ stigma describes the actual experience of discrimination. ‘Felt’ stigma describes a fear of discrimination that may cause people to behave in ways to reduce the possibility of ‘enacted’ stigma (Malcolm et al. 1998). In the context of hepatitis C, ‘felt’ stigma implies that people will often not disclose their positive sero-status and/or injecting drug use to those who may be in a position to discriminate against them for fear of negative consequences.

Whether discriminatory responses occur due to ignorance and/or a dislike of people who inject drugs, they reflect attempts to establish and maintain distance from the threat of disease and to uphold what are seen as important community values. The following describes a range of possible outcomes from disclosure, highlighting processes of stigmatisation and categorisation of people into out-groups.

## *F2. The ‘innocent’ and ‘guilty’ victims of hepatitis C*

It is apparent that communities make a distinction between ‘guilty’ and ‘innocent’ victims of some epidemics (Herek & Glunt 1988). Where an epidemic is associated with an already stigmatised population, blame for infection is attributed to the victims’ inherent deviance and aberrant lifestyle. Because injecting is a stigmatised practice and seen as a voluntary behaviour, the community positions injectors as ‘guilty’ victims of hepatitis C, justifying their exclusion from society’s concerns. Throughout the Enquiry, people living with hepatitis C repeatedly expressed concerns regarding the assumptions made by others relating to how their infection was acquired. It was common for health care workers, other service providers and people from the general community to label hepatitis C positive people as either ex or current injecting drug users, responsible for their own infection and therefore ‘guilty’ victims of the virus. A hepatitis C service provider claims that health care workers generally feel that people living with hepatitis C:

**‘ ... only have themselves to blame and that they are less worthy of health**

**care services because they are, or were, injecting drug users, even if fleetingly.'**

Similarly, this attitude was evident among people's friendship networks. Below an ex-user describes a 'friend's' reaction to her hepatitis C disclosure:

**'One 'friend' went so far as to say that those who contracted hep C through medical procedures or workplace injury are entitled to feel much more upset about having HCV than 'people like me'.**

Finally, a submission from a man with medically acquired hepatitis C implied that people are rational beings and must be held accountable for their own behaviour. Therefore, those with medically acquired hepatitis C should be put ahead of people who acquired the virus through injecting drug use when it comes to selecting people for places in treatment trials:

**' ... drug user(s) should be at a lower level ... everyone is responsible for their own action(s), drug users or otherwise.'**

### *F3. Discrimination of hepatitis C-related health care workers*

Claims were made at the Enquiry that health care workers discriminated against service providers who work in the hepatitis C and alcohol and other drugs (AOD) health services. Hepatitis C and AOD workers reportedly bear the stigma of their clients and were often assumed to be hepatitis C positive 'ex-junkies' by other health care providers. A worker starting a new job in the area of hepatitis C service provision claimed that a colleague remarked in an intimidating manner:

**'I suppose you have to have hep C to get that position'.**

Generally, health providers positioned AOD workers on the margins of health care. It was claimed that staff at needle and syringe programmes (NSP) were 'often at odds' with non-AOD health care workers who see NSP clients as undeserving of health care. Similarly, a health care worker who acquired hepatitis C from a needle-stick injury was advised by his solicitor and doctor not to disclose his status to fellow workers for fear of discrimination.

### *F4. The tools of harm reduction: resistance to drug-related health services*

Related to health care workers' and the general community's ignorance of hepatitis C infection was the often cited poor understanding of the role and place of needle and syringe programmes, methadone maintenance treatment and alcohol and other drug services in the public health system. In some centres, the media is claimed to manipulate hepatitis C issues to promote stigmatisation and discrimination, and media articles and reports do not mention the positive aspects of needle and syringe programmes, methadone prescribing and alcohol and other drug services. Several methadone maintenance clients as well as service providers reported discrimination and discussed the need for some health care workers and the community generally, to be re-educated about harm reduction and the benefits of needle and syringe programmes and methadone maintenance treatment. In some regions, needle and

syringe vending machines were vandalized. The suspects included local business people and community identities.

A worker from a methadone clinic reported aggravation from local business people who expressed their wish to see the clinic closed or moved out of their area. Similarly, a private methadone clinic was closed down in a regional centre due to agitation from the local community and in another region local business people have blamed a methadone clinic operating in the central business district for the downturn in local business. An aboriginal health worker indicated that it would be difficult to change attitudes in the aboriginal community about needle and syringe programmes because they are seen as ‘sending the wrong message’. Another worker believes that the Aboriginal Medical Service resists needle and syringe programmes and education campaigns regarding injecting drug use because the ‘older people’ who sit on the boards do not engage with the issue of harm reduction.

A service provider suggested that community ignorance and cynicism of harm reduction is reflected in the labeling of ‘Fit-packs’ as ‘Party-packs’ by some health care workers. Another health worker stated that a common attitude expressed by people in her Area Health Service is:

**‘ ... we’re not against harm minimisation, but not in our backyard’.**

#### *F5. Access to hepatitis C and other health services*

Discriminatory attitudes and practices from the health care sector were having an effect on people accessing hepatitis C-related and other health services, according to service providers. Some groups of hepatitis C positive people, like injecting drug users and people from culturally and linguistically diverse backgrounds, are not accessing a range of health services that could assist them due to fear of (further) discrimination. Service providers and individuals cite people using non-disclosure as a means to prevent discrimination and this is thought to affect which services are accessed. Also, hepatitis C-related discrimination was having an effect on health service provision for hepatitis C positive people, as highlighted by a CEO of an Area Health Service:

**‘ ... the ongoing discriminatory attitudes often held by health workers, including general practitioners, and those in the wider community hamper the further development of co-ordinated health and welfare services for people living with hepatitis C.’**

Some of these discriminatory practices concerned breaches of confidentiality and withholding of treatment.

#### *F6. Confidentiality*

Within health contexts, the careless handling of confidential information about hepatitis C patients was a significant theme within the submissions. Consistent with a prediction of social identity theory, there appeared to be less concern for the rights to confidentiality of stigmatised patients than for other patients. Confidentiality was

compromised through, for example: the use of colour-coded wrist-bands signifying hepatitis C to staff and anyone in the know; staff speaking loudly in a public ward about a patient's hepatitis C positive sero-status; and signs displayed above beds and easily legible to the public declaring 'Hepatitis C positive'. Breaches of medical confidentiality lead to relationship breakdown and personal information leaking into friendship networks, workplaces and among families.

Service providers cited particular difficulties among rural and smaller communities where the confidentiality of hepatitis C patients' health information was said to be hard to ensure as 'everyone knows each other'. A nurse reported that in rural settings, health care workers can often recognize hepatitis C positive patients through their descriptions and that this information is passed among other health care workers. Confidential medical records were erroneously completed and carelessly mishandled by doctors and nursing staff according to several submissions. A patient who disclosed his hepatitis C sero-status to his doctor with an explanation that he had acquired the virus after a blood transfusion, some time later observed that his medical file indicated he had had a history of unsafe injecting practice. In another instance, a patient's file was marked 'hepatitis C positive' and left at the end of the bed where a friend observed it. This information was then passed around the patient's social network resulting in loss of friends and exclusion from this network. Some patients reported that their blood test results were given to them over the phone. Similarly, service providers reported that sex workers were given their test results in a careless manner that compromised their confidentiality.

#### *F7. Poor medical treatment and exclusion from health services*

It was common among the submissions to hear reports of poor treatment by nurses, doctors and specialists of hepatitis C and injecting drug use patients in hospitals. Following disclosure of a positive sero-status patients were often placed last on the day's surgery list. This resulted in anger and frustration from hours spent waiting without food, sometimes in pain and often with no explanation. Examples were provided of health care workers using 'abusive, patronizing, paternalistic and condescending' language, such as in the case of a psychiatrist who took away a methadone patient's right to be chemist-dosed, telling his patient that he wanted him 'on a leash, a tight leash like an animal'. A sero-positive patient admitted to hospital for surgery was told by a nurse that she would be placed on 'the dirty list' and that 'her sheets would have to be burnt' when she left. A patient reported that he was not assisted to shave, was spoken to 'badly' and suffered bedsores when nurses avoided him after he had disclosed his hepatitis C positive status.

A number of people discussed their experience of being denied pain relief after disclosing their hepatitis C infection when presenting at hospitals and dentists. They believed that pain relief was denied because doctors assumed that the patients were injecting drug users. These assertions were supported by service providers from various Area Health Services in NSW. Hepatitis C patients found it hard to get pain relief if nursing staff or doctors knew the patient to be on a methadone maintenance programme or a current injecting drug user.

Exclusion from medical treatment and health services was cited by individuals and service providers. Exclusion exemplifies the creation of boundaries that social identity theory predicts will occur when specific groups or practices are deemed incompatible or threaten hegemonic group values. Claims were made that some general practitioners and dentists refused to treat hepatitis C positive patients. A dentist reportedly stated that he 'did not want to see people with viruses' in his practice, while doctors at a newly opened medical practice advertised that they did not want to see alcohol and other drug clients at their surgery. Several people reported that doctors and dentists had been 'unhelpful' in providing treatment or information regarding hepatitis C once patients had disclosed their positive sero-status.

Similarly, people claimed they were denied access to needles and syringes from some hospital emergency department outlets. A large user organisation stated that current injecting drug users are sometimes denied access to combination treatments for hepatitis C because of a belief that they cannot comply with drug taking regimens. Also, claims were made of sero-positive people being 'rushed through' health services while others commonly complained about receiving no pre or post-test counseling for hepatitis C blood testing.

### **G. Affective responses to hepatitis C-related discrimination**

The experience of discrimination can elicit a range of reactions and this was evident from the submissions to the Enquiry. Individuals and service providers attested to a significant degree of anger as a result of their experiences of discrimination. This was markedly apparent when discriminatory practices were encountered from the health care sector, particularly if it involved a doctor or a specialist. Patients described how they were often regarded with 'a complete lack of compassion' and expressed their anger and humiliation at being treated like 'untouchable(s)'. Some patients 'felt disturbed' at being ill yet considered by their doctor to be unworthy of medical treatment. Patients commented on their frustration at not being able to change their doctors' attitudes or educate their doctors about living with hepatitis C. As one man writes:

**'I felt frustrated, disappointed and angry and felt that the surgeon was not doing his job. I felt that I had been discriminated against [and] I felt like giving up on health care providers ... I found the whole incident very distressing. It was hideous. I feel shattered. It's changed my whole life.'**

In contexts outside of the health care sector, the experience of discrimination created similar negative affective responses in people. Evidence highlighted the difficulties people had, following the loss of a loved one, in dealing with grief and achieving closure as a result of discriminatory practices carried out by some funeral service providers. Anger was directed at large private sector organisations for their attitudes to, and discriminatory treatment of, employees who had either disclosed their sero-status or were suspected of having a chronic infectious disease such as hepatitis C. People also discussed processes of self-reassessment and re-evaluation that occurred because of the stressful effects of discrimination on their close personal relationships. A man who had been refused life insurance because of his hepatitis C positive sero-status writes:

**‘ ... my inability to provide financial security for my family has left me very worried about the future and totally demoralized ... [my wife’s] constant distress at my inability ... has had a detrimental effect on my confidence, self-esteem and ability to be a good father.’**

Finally, a divorcee writes about her ex-husband’s refusal to touch her following disclosure of her hepatitis C diagnosis. Here, she discusses her fear of further discrimination within future relationships:

**‘ ... [hepatitis C] has devastated my life, I know I will never be able to have an intimate relationship with a man because I would be [too] scared to tell, and I could not lie.’**

### *G1. Learned helplessness*

Submissions contained evidence of a learned helplessness (Seligman et al. 1980) operating among injecting drug users. If stigmatised people have experienced poor treatment in the past, they may come to expect further discrimination and integrate these negative experiences into their sense of self. As in a state of learned helplessness stigmatised people who have experienced ongoing discrimination may be unmotivated or unable to seek redress. Evidence from a community legal centre stated that members of some marginalised groups, such as injecting drug users, are so used to discrimination they can no longer objectively perceive it when it occurs:

**‘An act of discrimination on the basis of hepatitis C status may be difficult to discern for a person who is treated with a lack of respect on an everyday basis as ‘dirty’, ‘immoral’ or ‘subhuman’ by fellow citizens.’**

A common attitude found among injectors, and discussed in submissions from a range of organisations, related to people’s aversion to making formal complaints with regard to hepatitis C-related discrimination issues:

**‘I’m sick and tired of not having complaints acted upon. I don’t complain anymore.’**

**‘Who would you complain to ... and would they really care?’**

## **H. Societal forms of hepatitis C-related stigmatisation and discrimination**

It has been observed that in Australia hepatitis C policy was slow to develop when compared with the urgency that governments exhibited in their response to the HIV epidemic (Hulse 1997). One reason for this is the view that the virus is largely confined within injecting drug user populations and is regarded as unlikely to cross over into mainstream Australian society. Hulse argues that policy was slow to develop because injecting drug users are perceived by the health bureaucracy as disorganised and do not constitute a ‘community’ in the same sense as the gay community that helped to enable an efficient response during the early years of the HIV epidemic. He points out that power for making and informing public health policy concerning hepatitis C has shifted back to senior health bureaucrats and away from giving a role

to ‘affected’ communities (Hulse 1997). It is likely that such bureaucratic stigmatisation endangers the development of relevant policy sensitive to the needs of a diverse population as represented by the ‘hepatitis C community’. Bureaucratic apathy concerning this epidemic has contributed indirectly to hepatitis C-related discrimination (Hulse 1997). Denial by governments of the existence of an epidemic and those most affected by it may have contributed to increasing the isolation and stigmatisation of people living with hepatitis C while simultaneously discrediting their needs. The experience of HIV/AIDS in some countries of the world has illustrated how this occurs (Malcolm et al. 1998).

Injecting drug use is a most efficient vector of hepatitis C transmission, however, Federal and State governments in Australia are reluctant to engage with the issue of drug law reform. Generally, voices seeking drug law reform as a means by which to reduce viral transmission and address a range of health related issues for people living with hepatitis C were notably scarce throughout the Enquiry. Calls for drug law reform were usually expressed as an aside or delivered as part of a ‘wish-list’, something that people would like to see happen but something they felt was years and possibly decades away. In the meantime, a key stakeholder in the field of alcohol and other drugs commented that current drug policy is exacerbating the risks for hepatitis C virus transmission. Some service providers and individuals suggested drug law reform as an option to reduce viral transmission as well as hepatitis C-related discrimination. A submission from a prisoners’ advocacy organisation blames society’s prohibitive stance on drug use as ‘one of the leading risk factors to public health in NSW’ because of the level of hepatitis C infection within prisons and the ease at which it can be transmitted in that context and in the wider community:

**‘While so much has been achieved in the wider society to ... lower [hepatitis C] infection rates, the prison system and its discriminatory practices is actually an institutional incubator threatening to undermine wider social policy, practice and safety.’**

This organisation suggested that by reducing the number of people receiving prison sentences for drug offences, the incidence of hepatitis C infection in society, as well as hepatitis C-related discrimination, would be reduced.

## **I. Conclusion**

This document provides an analysis of the central themes to emerge from the submissions tendered to the Anti-Discrimination Board of New South Wales’ Enquiry into Hepatitis C-related Discrimination. In order to gain some understanding of the nature of hepatitis C-related discrimination, submissions to the Enquiry are viewed and discussed through the theoretical lens of stigma and social identity. The document highlights society’s confounding of hepatitis C infection with injecting drug use and the influence that this has on the individual experience of discrimination. The analysis describes the experience of hepatitis C-related discrimination as evident from the submissions to the Enquiry. Poor knowledge of hepatitis C, disclosure, confidentiality, ‘userphobia’, and health care workers’ discriminatory practices and attitudes are highlighted. The negative impacts of discrimination on individuals’ sense of self and the implications this has for people accessing hepatitis C-related services are

discussed. Finally, societal forms of hepatitis C-related stigmatisation and discrimination are highlighted with allusion to the role of drug prohibition in hepatitis C-related discrimination.

This interpretation of the submissions to the ADB Enquiry raises several important aspects regarding hepatitis C-related discrimination. Ignorance of hepatitis C and the confounding of the virus with injecting drug use create the context for discrimination.

The relatively recent discovery of the hepatitis C virus and its high prevalence among sub-sections of the general community establishes a set of dynamics for the perpetuation of misinformation regarding, for example, transmission risks, infectiousness and disease prognosis. While knowledge within the general community regarding hepatitis C is scant, evidence from the Enquiry shows that even among health care workers hepatitis C is often a misunderstood virus. As predicted by stigma and social identity theory, some uninformed sections of the community are reacting to people living with hepatitis C in discriminatory ways in order to preserve their distance from risks of infection. Stigmatisation of those people living with hepatitis C, through labeling them as 'sick' and infectious, is deployed as a method of preserving the physical health of communities against the complications represented by the disease.

Where people are assumed to have contracted hepatitis C infection from injecting drug use, an alternative set of dynamics are established with which to view hepatitis C-related discrimination. Judgments concerning an individual's moral and personal adequacy are made via a process of categorization that positions people with the virus as 'deviant', that is, existing outside the boundaries of accepted normal social behaviour. This establishes an 'us' and 'them' binary where injecting drug users are perceived to belong to a homogeneous out-group that has a lifestyle informed by a value system inconsistent with, and inferior to, the majority of society. This out-group is characterized as having prioritized pleasure above physical health, compromised their rationality, and participated in illegal activities. Members of the out-group are viewed as a danger to themselves, those close to them and, indeed, the general community. People with hepatitis C are judged as 'guilty' victims and responsible for their infection, justifying discrimination by the non-using majority. The fear and dislike of injecting drug users helps explain why users: receive poor treatment from a variety of social institutions; may be denied pain relief in hospitals; have their rights to confidentiality in medical settings violated; receive increasingly under-funded services; may at times be totally excluded from health care; and are held personally responsible for their physical, moral and social impoverishment.

Many of the submissions to the Enquiry pointed to the health care system as a primary source of hepatitis C-related discrimination. Submissions from both individuals and health care workers highlighted instances of discrimination. Because people living with hepatitis C are more likely to disclose their positive sero-status to doctors, dentists, specialists and nurses than in other community contexts, health care is a key setting in which hepatitis C-related discrimination is likely to be enacted.

Continued discrimination and stigmatisation of people living with hepatitis C will obstruct efforts to prevent the further spread of the virus among the community. Hepatitis C-related discrimination is extensive and is a complex social problem that

encompasses many secondary issues. Addressing community ignorance of the virus may assist in ameliorating some people's experiences of discrimination, however, increased knowledge alone will not be sufficient to address hepatitis C-related discrimination within all domains. As theory suggests, discrimination of people living with hepatitis C may serve a socially adaptive function for certain groups by reinforcing cultural norms and values that are at odds with people who belong to, or are perceived to belong to affected groups, such as injecting drug users. Legislative change may be the first step in a process to counter stigmatisation and discrimination of people living with hepatitis C. Law reform could pave the way for broader changes in the attitudes and social norms that currently inform discriminatory practice.

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