

chapter 3

Discrimination
experienced
by particular
communities

3.1 Introduction

The nature of hepatitis C discrimination, particularly the contexts in which discrimination occurs, has been explored in detail in Chapter 2. Through the analysis it is evident that experiences of discrimination may differ for different population groups or communities. The experience of discrimination by particular groups or communities often has unique qualities, particular implications and/or needs to be understood within a broader context.

This chapter briefly highlights the unique co-factors or contexts that are particular to some communities. Some of the issues raised in this chapter are beyond the scope of the Enquiry, for example, the Enquiry is not in a position to make recommendations to address the breadth of issues affecting Indigenous people's health. Nonetheless, highlighting these broader issues gives a more accurate picture of the nature of hepatitis C discrimination in particular communities. Other issues raised in this chapter have a direct bearing on hepatitis C related discrimination and are drawn together here to ensure that the Enquiry report accurately reflects the nature of discrimination as it is experienced by particular communities. Generally, these issues have been considered and, where appropriate, recommendations made in Chapter 2.

3.2 People who have, do or are assumed to inject drugs and people on drug treatment programs

The evidence to the Enquiry makes it abundantly clear that the stigma associated with injecting drug use is closely linked to hepatitis C, and discrimination on the basis of hepatitis C or current, past or assumed drug use are so closely associated that they may be indistinguishable.

Drug users are often left guessing themselves as to what the discrimination was based on. Were they discriminated against because of their drug use or because of their hep C status or because of their methadone treatment. Often they're not sure¹

The interrelationship between hepatitis C and injecting drug use, including the lack of clarity regarding the coverage of drug dependency under anti-discrimination laws, has been considered in detail in Chapter 2, section 2.2. Nonetheless, it is important to highlight the nature of discrimination against people who inject drugs and the implications of this discrimination both in terms of health outcomes for people who have injected or currently inject drugs and for hepatitis C prevention efforts.

Evidence to the Enquiry indicates that people who inject illicit drugs and those who are on methadone programs, whether hepatitis C positive or not, are subject to considerable discrimination. Concerns regarding confidentiality, access to and treatment within the health system, and discrimination in employment all feature prominently in the evidence to the Enquiry.

Examples include:

- discriminatory treatment on the basis of drug use in hospitals, particularly in relation to the manner in which services are provided and refusal to provide treatment
- discriminatory treatment in access to needle and syringe programs
- discrimination in access to accommodation
- discriminatory treatment in the provision of dental services
- discriminatory termination of employment.

¹ Ms Maureen Steele, Sydney hearing, 15 March 2001.

Discrimination against people who have injected, do inject or are assumed to inject drugs

Precisely because of the confounding of hepatitis C and drug use, the Enquiry received considerable evidence highlighting discrimination on the basis of current or past drug use per se, particularly in health care settings. This has significant implications for the health of injecting drug users generally, regardless of whether they have hepatitis C, as well as for those with hepatitis C and for hepatitis C prevention efforts.

...injecting drug users experience so much discrimination anyway, or expect to experience it, that hep C is just another layer. They might not even realise that they're being discriminated against on that basis because for them it's about being a user.²

Many examples of discrimination on the basis of people's past, assumed or current drug use have been considered in detail in Chapter 2, as many submissions to the Enquiry demonstrate the interrelationship between discrimination on the basis of drug use, assumed drug use and hepatitis C status. As previously outlined, the nature of discrimination on the basis of current or past injecting drug use, is often based on stereotypes about people who inject drugs, such as assuming that people who inject drugs do not care about their health and have chaotic lifestyles. Evidence indicates that the range of people who have injected or do inject drugs is diverse and does not readily fit these simplistic stereotypes.³

Because of injecting drug use's association with illegal activity, people who inject drugs are often perceived to be engaging in deviant behaviour and inflicting self-harm. This often leads to a stereotype that injecting drug users are out of control, anti-social and have a chronic addiction. While this may be true for some, this kind of labelling is unhelpful and not an accurate reflection of the vast majority of people who inject, or have injected, drugs.⁴

It is often the case that community stereotypes of drug use, and of people who inject drugs in particular, do not stand up to scrutiny. They may have little or no connection with available evidence.

Films like *Trainspotting* paint a very inaccurate picture of what it is to be an injecting drug user in Australia ...just as not all drinkers are alcoholics, not all injecting drug users are addicts. We have found a diverse study of injecting drug users to in many ways be no different from other people in the community, except they inject drugs.⁵

A considerable amount of drug use is neither abusive nor problematic to the individual or the community, and is of an experimental or recreational nature. For those who commence heroin use, many do so only for short periods (weeks or months). Among those who develop regular patterns of heroin use, 10 % have ceased to use heroin by the end of the first year and 40% have stopped by the end of 10 years.⁶ Most people who inject drugs do not inject every day.

A study undertaken by The Centre for Research into Prevention of Drug Abuse found that:

- 47% were employed, of these most were in full-time jobs.
- 5% were studying
- 12% cared for their children and/or families at home
- only 30% were unemployed
- Less than 10% of are engaged in dealing drugs or other criminal activities
- Fewer than 5% were homeless, with most renting or paying off a mortgage
- 44% of people who inject drugs are married or in de facto relationships, and over 40% are carers of children
- 80% of injected drugs within their own home.⁷

A lack of understanding of the causes of drug use often underpins stigmatisation of people who have injected or do inject drugs.

² Ms Maureen Steele, Sydney hearing, 15 March 2001.

³ See Chapter 2, section 2.2 for a detailed discussion.

⁴ HCC NSW, Submission No. 80.

⁵ Lenton, S. *Not all drug injectors are addicts - New Study*, Media Release, Curtin University of Technology.

⁶ *Drugs and Our Community*, Report of the Premier's Drug Advisory Council, Victoria, March 1996, page 19.

⁷ Lenton, S., Tan-Quigley, A. 1997 *Fitpak Study: A survey of 'hidden' drug injectors with minimal drug treatment experience*. Perth, Western Australia: National Centre for Research into the Prevention of Drug Abuse, Curtin University of Technology.

Some members of my support group... have told the gathering that they believe their illness is 'payment' for their 'sins'. I am deeply saddened when people voice this internalised userphobia that I have also experienced. It leaves little room for discussion or even consideration of the complex health, social, political and psychological issues that surround injecting drug use. It's also somehow an acceptance of poor health and being treated in a shabby manner... It makes me feel angry and hurt that many people seem to believe that those of us who have hep C as a result of injecting drug use somehow 'deserve' this illness and the social stigma it carries...⁸

The mere fact that a person has a history of injecting drug use or is currently using illicit drugs should not be arbitrarily used as a rationale for denying people access to services or employment. The social analysis undertaken by the National Centre on HIV Social Research considers the stigmatisation of drug use in some detail and explores the stereotypes that often lead to discriminatory treatment of people who inject illicit drugs, have done so in the past or are assumed to do so: see Appendix E.

Because of the way society views illicit drug use and injecting drug users, people are socialised 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... 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.⁹

Evidence to the Enquiry indicates that people who currently inject or have injected drugs in the past are most likely to experience discrimination in the health care system. The Australian Hepatitis Council cites both general practice and hospitals as a key context in which discrimination occurs against people who have injected, do inject or are assumed to inject drugs. This is echoed by many other submissions to the Enquiry.¹⁰

General practice remains a particularly hostile environment for many people who have, or who are assumed to have, a history of injecting drug use... commonly resulting in reduced treatment options and inadequate quality of care, particularly in relation to pain relief.¹¹

Both the national and NSW hepatitis C strategies commit to ensuring that current or past drug use should not be used as a ground to restrict or deny people access to health care and other services.¹² However, it appears common for people who inject illicit drugs to be refused medical attention on the basis that their drug use diminishes their right to health care.

Some of the comments you get from health care workers in the secondary [NSP] outlets are: 'we don't want those sorts of people hanging around our hospital', 'I've got better things to do than to deal with them', 'they offer nothing to our community, they give nothing back into our community so why should we deal with them'.¹³

In evidence to the Enquiry, Dr Ingrid van Beek, Director of the Kirketon Road Centre stated that it is often difficult to refer clients of the Centre to other health services, because their clients commonly experienced such high levels of discrimination that they were unlikely to obtain the services they sought, or where they did access the service, the treatment they received would deter them from returning for follow-up treatment.¹⁴

At times we feel we almost have to be careful about not giving people too great expectations about what their rights are going to be when they're not actually realised... if you're an injecting drug user you didn't only go to the bottom of the list, you were dropped off the list altogether... there does seem to be an underlying assumption that once a drug user, always a drug user.

It's an extreme example, but when an ambulance comes to the casualty department with someone who's had a... heart attack, we don't stop that person at the door and say 'have you smoked cigarettes in your lifetime? Because if so we feel this is self-inflicted and we don't believe you have the same right to be resuscitated at this point in time.' So clearly we hold very different values, as a community, broadly in respect to illicit behaviours.¹⁵

Evidence to the Enquiry also indicates that treatment of injecting drug users by police is an ongoing issue,

⁸ Individual Submission No. 46.

⁹ See Appendix E at section C2.

¹⁰ Examples include: HCC NSW, Submission No. 80; NUAA, Submission No. 68; AIVL, Sydney hearing, 2 August 2001; and ANCAHRD HCV Committee, Submission No. 47.

¹¹ AHC, Submission No. 60.

¹² *National Hepatitis C Strategy* at page 48 and *NSW Hepatitis C Strategy* at page 24.

¹³ Health care worker, regional hearing, May 2001.

¹⁴ The Kirketon Road Centre is a specialist drug and alcohol service.

¹⁵ Dr Ingrid van Beek, Sydney hearing, 2 August 2001.

particularly in the manner in which methadone clinics and needle and syringe programs are subject to surveillance contrary to police guidelines. This issue is considered in detail below.

On one participant's [NDARC study] police file was written the participant's positive HCV status. This resulted in verbal abuse with the participant being called a junkie, told he does not deserve to live and being labelled a 'disease carrier'.¹⁶

Discrimination against people on methadone programs

Case study

I had worked for the same department for nine years. I had an exemplary record. I was an honest, hardworking, dedicated and trusted employee. Throughout my nine years in the job I was on methadone and had been for six years before I started that job. Nobody knew I was on methadone. I didn't fit society's stereotype image of a 'junkie', I was well dressed, well groomed, well spoken and highly educated. I had to go to the pharmacy twice a week for my take away doses. I decided to move to a pharmacy closer to home... that move turned out to be the beginning of my 'nightmare'.

At first everything was OK at the new pharmacy. After a while the pharmacist seemed to become very curious about me. He said he had never had a client like me before and that I didn't fit the image of a heroin addict. He started asking questions about my family, education background etc. It was through this line of questioning that I (very stupidly) disclosed my occupation and work place. I didn't know it at the time, but the pharmacist was a close personal friend of one of my colleagues in my office. The pharmacist told my colleague that I was one of his methadone clients. The colleague immediately notified my work supervisors and told them...

My supervisor called a meeting with me and said 'It has come to our attention that you are on methadone' she said, as I entered the meeting room. My heart sank, my worst nightmare had just come true in those 11 words. I didn't know what to say or how to respond. I had to say something so I denied it. The next few weeks were the worst of my life. Everybody in the office was whispering about me. My 9 years exemplary work history, all my hard work, my reputation, everything went out the window. I was no longer a highly respected professional and authority in my field, I was a drug addict — a dirty diseased junkie within their ranks. An environment of hep C hysteria started to invade our office. There were comments like 'Oh my god, I think I used the staff toilet after her' and 'I drank from the same cup as her — now my whole family will have to be tested for hep C and HIV'.

I put up with this nonsense for about 4 weeks. Finally the Regional Director told me that if I wanted to retain my job with his department I would have to prove to him that I was not on methadone now or at any stage during the past 9 years working in the department. After the meeting with the Regional Director, I gave 2 weeks notice and resigned. The stress was incredible. It affected my health severely. Thanks to the stigma of being on methadone and the perception of all methadone recipients being hep C positive my career was over. Just like that... I went to interviews for a new job but this raised more problems. I was short listed for a few jobs but when they got to the stage of ringing my last employer, my prospective employers were told that I was on methadone and have HCV.

One convenor of an interview panel told me that even though I was the most qualified candidate for the job, he could not give it to me as the department was not equipped to deal with an employee on methadone and did not have the 'infrastructure' to support a HCV+ employee... by infrastructure he meant sterilisation equipment for my office. Once again my being on methadone had nothing to do with my ability to do the job, yet I was unemployable.

I tried everything I could think of to find out if what was happening to me was legal or not. But nobody could give me any info. I rang the union for help, but they were unable to find any policies that could act as a guide for methadone. I had no support — So what did I do? I finally gave up, I copped it sweet.¹⁷

¹⁶ NDARC, Submission No. 59

¹⁷ Individual Submission No. 96.

Evidence to the Enquiry indicates that people are as likely to experience discrimination on the basis that they are on a methadone program, as they are on the basis of past, assumed or current illicit drug use.

...drug users have the right to access all the same facilities in the community as people who don't use drugs... they have the right to move through certain areas, they have the right to sit, they have the right to attend coffee shops...we have people who are on methadone and even though they've done nothing wrong in the area they have been told to leave coffee shops just because they're known to be on methadone.¹⁸

case study

A longstanding patient...who enjoyed her work as an enrolled nurse...finally took my advice and started methadone, after battling to control her heroin use for 12 years...After 2 weeks she looked good and felt that it had been the right decision. Six weeks later she received a letter from the Nurses' Registration Board demanding a review as she was receiving methadone. There had been no problems with her work, and as an enrolled nurse she never held the drug cupboard keys. I had never felt a need to notify the Board when she was using heroin (and had discretely checked with her supervisor who told of her exemplary work), let alone when she was settled on methadone! After several disputes, she was ordered to provide urine tests thrice weekly at her expense!...[She] suffered considerable humiliation and episodes of inconsolable despair and anger, she has left nursing and left the town, having lost her car, house, job and self esteem.²³

The stereotypes which often motivate discrimination against people who inject illicit drugs appear to be applied just as readily to people on treatment programs. The Enquiry heard evidence that staff from a methadone clinic were regularly called by local shop owners to attend the shopping mall alleging a client of the clinic was seen behaving in a way that people thought wasn't acceptable.

Nine times out of ten when we're called down [to the mall] because 'a client was seen' behaving in a way that people thought wasn't acceptable, they are not our clients, I have no idea who they are.¹⁹

Once marginalised, they can be subjected to significant discrimination without arousing the normal concerns or...protections that others take as part of our democracy.²⁰

A health worker in a methadone clinic told the Enquiry that a client of his, who worked in the computer industry, was waiting outside for the methadone clinic to open before he went to work. Somebody from his company drove past and saw him there. He was sacked the next day, not because his performance was poor, but solely because he was seen outside the methadone clinic.²¹

A drug and alcohol specialist described numerous incidents where his clients had been subject to discrimination because they were on methadone.²² One of his clients, a 30-year-old man, attended him in his clinic after he had fallen from his pushbike the previous day and could hardly walk, and had significant shoulder pain. The Doctor arranged a review at the accident and emergency department next door and escorted his client to the hospital.

I was told to see the triage sister, who had seen me and my patient, rolled her eyes and left the desk. I spoke with the Director and he was sat beside a bed. I had explained that we needed a diagnosis for his leg pain and swelling and his shoulder pain, and that he lived alone and was almost immobilised, so was most puzzled when he was kept waiting two hours then sent home. The intern felt, apparently, that he had injected into his leg muscle and had an abscess. Three days later he was admitted for surgery to evacuate a huge haematoma from a ruptured thigh muscle, and his fractured shoulder was detected on X ray. A nursing student with our Unit who was present throughout this display of passive hostility suggested she 'punch her (the triage nurse) in the head' which at least confirmed my view that it's not just me who detects this discriminatory behaviour.²⁴

Impact of the criminalisation of drug use

The criminalisation of drugs creates the fertile grounds in which HCV is able to thrive...any real attempt to control HCV and HCV discrimination must seek to introduce better and more humane methods of drug control. We argue that a change from the criminal justice model to a health and education-based model would most likely lead to effective control of HCV.²⁵

¹⁸ Health care worker, Wollongong hearing, 9 May 2001.

¹⁹ Health care worker, regional hearings, May 2001

²⁰ Dr A. R. MacQueen, Submission No. 97.

²¹ Health care worker, regional hearing, May 2001.

²² Dr A. R. MacQueen, Submission No. 97.

²³ Dr A. R. MacQueen, Submission No. 97.

²⁴ Dr A. R. MacQueen, Submission No. 97.

²⁵ NUAA, Submission No. 68

I'd like to see acknowledgment and understanding of drug issues as a health issue... a huge push behind that and the principles of harm minimisation...²⁶

The fact that injecting drug use is an illegal activity creates a significant tension between responses to injecting drug use which are focused on health outcomes and those which are focused on law and order outcomes.²⁷ Numerous submissions emphasise that policies and legislation which focus on drug use as a criminal issue, rather than a health issue, legitimise discrimination against people who have injected or do inject drugs.²⁸

Drug policy and law reform is at the crux of information, knowledge, education and discrimination around HCV. While injecting drug use remains an illegal activity it almost gives credence or gives the general community and the media the right to discriminate against people with HCV and injecting drug users specifically.

...the discrimination that people experience related to their hepatitis C diagnosis is inextricably linked to the fact that the most common mode of transmission is injecting drug use and the fact that injecting drug use is an extremely stigmatised behaviour. It's important then to ask the question 'Why is that so?' and then inevitably the fact that injecting drug use does continue to be a criminal behaviour must be a very important cause of that discomfort and discrimination. People make very strong judgments about people who engage in illicit behaviours.²⁹

The impact of the criminalisation of drug use has clear consequences for hepatitis C prevention efforts. For example, self administration (or 'use') of prohibited drug remains an offence in NSW.³¹ The existence of this offence contributes to the fear among people who inject drugs that possession of injecting equipment can be used by police to gain an admission of use and can be used as evidence to support the charge. This is so regardless of whether or not this occurs in reality. As a result the offence acts as a disincentive to people to carry sterile injecting equipment and increases the likelihood that people will share such equipment.

The offence of use is actually unnecessary for law enforcement purposes. The repeal of the offence of use would not alter the capacity to lay criminal charges in the case of possession of a prohibited drug and police practice strongly suggests that the offence of self administration is rarely used as a stand alone offence.³² Despite the cogent rationale for repealing the offence and strong support from the NSW Drug Summit, the NSW Government has not repealed the offence.³³

Both the national and NSW hepatitis C strategies seek to balance the illegality of injecting drug use with the importance of interventions which support the health of injecting drug users and reduce the risk of HCV transmission. They also recognise harm reduction as an essential component of Australia's hepatitis C response.³⁴

Harm reduction interventions are designed to reduce drug-related harm such as transmission of hepatitis C, both individuals and communities... there is compelling evidence that harm reduction interventions such as peer education and NSPs continue to be highly effective in reducing risk behaviour in the transmission of blood borne viruses.³⁵

Evidence to the Enquiry indicates that, despite clear national and NSW Government support for harm reduction strategies, including needle and syringe programs and drug treatment programs, negative community attitudes towards drug use have a direct impact upon the willingness of communities, community leaders and government agencies to support harm reduction measures. The Enquiry heard many

“ There's a need to put a human face on drug injecting... the critical issue really isn't how you would like somebody else unrelated to you to be treated, the critical issue is how you would like your son or your daughter or your brother or your sister or your cousin, how you would like that person treated.³⁰

²⁶ Health care worker, regional hearing, May 2001.

²⁷ Discussion of injecting drug use here refers to use of illicit substances. There are medications, including hepatitis C medications, which are administered by injection.

²⁸ For example: NUAA, Submission No. 68; Positive Justice Centre, Submission No. 78; and HCC NSW, Submission No. 80.

²⁹ Dr Ingrid van Beek, Sydney hearing, 2 August 2001.

³⁰ Dr Alex Wodak, Sydney hearing, 2 August 2001.

³¹ Section 11, *Drug Misuse and Trafficking Act* 1985.

³² The experience in Queensland, which does not have a use offence, provides evidence that the offence is unnecessary for effective drug law enforcement.

³³ *NSW Drug Summit 1999 - Government Plan of Action*, NSW Government, July 1999, Sydney. The Government's response cites the Drug Summit's recommendation 6.12 at page 75. The NSW Drug Summit recommended that Section 11 of the Drug Misuse and Trafficking Act 1985 dealing with use or possession of equipment for use in the administration of a prohibited drug should be repealed.

³⁴ *National Hepatitis C Strategy*, at page 11 and *NSW Hepatitis Strategy*, at page 4.

³⁵ *National Hepatitis C Strategy*, at page 14.

examples of resistance to needle and syringe programs and methadone programs by local councils, community leaders, local police, chambers of commerce and Area Health Services, particularly in regional and rural communities.

One regional health worker expressed grave concern about the lack of a face-to-face service at a primary needle and syringe program outlet. The fact that there had been no face-to-face service at a primary outlet had meant high turnover of needle and syringe program workers as a result of job dissatisfaction, as there were no prospects for building relationships with clients and thus achieving good health outcomes for those with hepatitis C and those most at risk of infection.

It's hindering a lot of education and prevention methods for HCV because the client contact is minimal. An NSP service is often the first point of contact for an IDU for any sort of health care, probably the only point of contact with the health care setting that they will get. Without that face-to-face service all those people fall through the gaps...³⁶

Another regional health care worker stated that the Area Health Service was not prepared to put their logo on the fitpacks distributed by the needle and syringe program they funded. The Enquiry heard of many examples of difficulties with local councils over provision of needle and syringe programs and needle and syringe disposal arrangements.

We've got some quite distinct problems as far as getting them to understand that they have any sort of responsibility as far as community waste is concerned...they seem to think that if we just stopped giving out needles and syringes then they wouldn't have a problem with them being in the community.³⁷

Some Indigenous health workers expressed concern about the lack of support within the Indigenous community, particular from community elders for needle and syringe programs, and this, coupled with fears about confidentiality, leads to reduced access to needle and syringe programs for Indigenous people who inject drugs.

The majority of Aboriginal elders [in this area] are not really engaged in health issues surrounding IDU, sexual health, NSPs.³⁸

Aboriginal people accessing Aboriginal organisations is another obstacle.

There are fears around confidentiality.³⁹

We've been working with the Aboriginal Health Services in a cooperative approach...the Aboriginal service providers are a bit reluctant to make the [injecting] equipment available and clients are reluctant to approach them anyway...⁴⁰

However, the Enquiry also heard evidence about the importance of Aboriginal controlled health services working within their own communities to increase understanding of and support for harm reduction initiatives.

The Redfern Aboriginal Medical Service and all the other Aboriginal Medical Services [AMSs] in the State support NSPs. AMSs are run by Aboriginal boards that are elected from their communities so when it comes to speaking officially about Aboriginal health that position of support for NSPs is adopted. As far as we know, the Aboriginal Medical Service in Redfern was actually one of the first organisations anywhere to set up a NSP. That was done unofficially in 1984 as it became clear that AIDS was communicable through blood.⁴¹

In 1997 the Drugs Programs Co-ordination Unit of the NSW Police Service published *NSW Police Service guidelines for support of needle and syringe exchange and methadone programs*, which makes it explicit that the NSW Police Service supports needle and syringe programs and methadone programs as essential public health programs, and commits the police to providing mutual support and assistance in the delivery of these programs. The guidelines make it clear that while police are responsible for law enforcement, they should be mindful not to carry out unwarranted patrols in the vicinity of needle and syringe programs and methadone clinics as such surveillance can discourage people from using these facilities. The policy states that police surveillance may be warranted when police presence is requested by workers, for example when workers are in danger or there is possible danger to the premises, or when police are in pursuit of someone they believe poses an immediate threat to clients or staff.

³⁶ Health care worker, regional hearing, May 2001.

³⁷ Health care worker, regional hearing, May 2001.

³⁸ Indigenous health worker, regional hearing, May 2001.

³⁹ Indigenous health worker, regional hearing, May 2001.

⁴⁰ Health care worker, regional hearing, May 2001.

⁴¹ Dr John Daniels, Redfern AMS, Sydney hearing, 3 August 2001.

Such clear policy support is obviously of critical importance. Nonetheless, the Enquiry heard numerous examples of police surveillance of needle and syringe programs and methadone clinics that appeared to be contrary to the police guidelines.

Police would come and park right in front of the methadone clinic but then go on to meetings in other parts of the hospital but put the police car with all the lights and sirens right out the front [of the clinic].

The NSP vending machine is also on the wall of that area so it makes it very difficult for people to access clean needles.⁴²

A guy was riding his push bike up to get dosed and he was ordered [by police] off his bike and [they said] 'Where did you get that bike? You must have stolen it...'⁴³

Two or three police officers come on a regular basis and wait for the clients to come out of the clinic, they stop the car, open up the car, check the car, check the wallet, check the licence, check the registration and sometimes it can happen day after day after day...⁴⁴

Recent research into the impact of police strategies in Cabramatta has found that:

...policing strategies threaten the tentative alliance between drug users and health professionals by displacing or driving drug users underground. Forcing heroin users to move around marginalises and alienates them from communities and the rest of society, hampering close contact and outreach efforts directed at this population.⁴⁵

Evidence to the Enquiry indicates that the lack of community and institutional support for proven harm reduction strategies is symptomatic of the stigmatisation of drug use and people who use illicit drugs and the lack of strong leadership for the benefits of harm reduction.

I think we need to engender more ownership of the drug problem rather than each community pretending that it doesn't belong there and it should be somewhere else, and it's come from elsewhere...⁴⁶

The needle and syringe program in Australia is an internationally recognised program. It is one of the world's best examples of prevention of viruses. But it seems to me that health departments...are just constantly on the back foot about that program. And I've never seen it sold in a really positive light. I've never seen a process to just kind of say, 'well deal with it' — this is an amazing program and it's done these amazing things for the entire Australian community, not just people who access that program.⁴⁷

The impact of discrimination

One of the most damaging consequences of discrimination against people who inject drugs is the impact such discrimination has upon their health. The evidence indicates that discrimination against people who inject drugs alienates them from access to health care. This has a detrimental effect on the capacity of the health system to assist people who inject drugs, including for drug related health problems. In addition, such alienation reduces access to hepatitis C treatment and care for people with hepatitis C and isolates those most at risk of infection from information and support to reduce the risk of hepatitis C, thereby undermining hepatitis C prevention efforts.

In the experience of the Australian Intravenous League, the fact that discrimination often leads to people who inject drugs failing to attend to their health also feeds stereotypes about injecting drug users.

“ The impact of regular and routine discrimination or the expectation of discrimination has resulted in drug users, en masse, staying away from key health services. The fact that drug users ignore hepatitis C symptoms for as long as they can, until they can not ignore those symptoms any longer, is considered to be just more evidence that drug users are lazy and do not care about their health... The reality is that they are so scared about the treatment they will receive, and/or are so sick to death of the attitudes that they get when they identify as an injecting drug user, that they will do and put up with almost anything to avoid that treatment.⁴⁸

⁴² Health care worker, regional hearing, May 2001.

⁴³ Health care worker, regional hearing, May 2001.

⁴⁴ Health care worker, regional hearing, May 2001.

⁴⁵ Maher, L. and Dixon, D. 2001 The cost of crackdowns: Policing Cabramatta's heroin market, *Current Issues in Criminal Justice*, Vol. 13, No. 1, at page 9.

⁴⁶ Dr Ingrid van Beek, Sydney hearing, 2 August 2001.

⁴⁷ Ms Annie Madden, AIVL, Sydney hearing, 2 August 2001.

⁴⁸ Ms Annie Madden, Sydney hearing, 2 August 2001.

The Hepatitis C Council of NSW emphasises the health implications for people who inject drugs and have hepatitis C. In the experience of the Council, discrimination against drug users from within the health system can result in signs and symptoms of hepatitis C or other conditions being misdiagnosed or misinterpreted.

The fact that many people who inject drugs will choose not to access health services in order to avoid discrimination has even more grave consequences for sections of the drug using population who are additionally marginalised because of other factors.

When an already stigmatised, discriminated population is affected by something like HCV, the discrimination almost becomes systemic. For the health system to not acknowledge and recognise that and address that is at best tantamount to a passive type of discrimination. Then when we take it up a further level and think about the marginalised drug using population...people who are doubly marginalised...such as people of Aboriginal origin, young injecting drug users, homosexual injecting drug users, transgender [people] and those of non-English speaking background. We really start to see how the system is failing those for whom it really ought to be catering for additionally.⁴⁹

The Enquiry supports the need for services that are appropriate for people who inject drugs or are on drug treatment programs. The importance of services designed to enhance access to services by people who inject drugs or who are on methadone is well illustrated by a successful regional dental program. Health workers in a local methadone clinic recognised the ongoing dental problems many of their clients had because of the methadone, coupled with their clients' anxiety about going to the dentist. In conjunction with a dentist in charge of the Area Health Services dental program, they set up a project to try and maximise their clients' access to dental care.

A dentist came with his collapsible chair and set it up in our little counselling room and did an initial assessment on everybody. For urgent cases, he gave them a voucher to see a private dentist so they could get it done for free. For others he put them on a list for routine check ups. All our methadone clients were targeted to have extra dental care. We found out that people were not presenting to the dentist because it was going to hurt too much. Pain relief may not work because they have such a high tolerance. This dentist came up with appropriate pain management strategies for those clients and put together information to give them about cleaning their teeth and maintaining them well. The same dental service goes out to smaller towns in a caravan.⁵⁰

Barriers to accessing needles and syringes have significant consequences for individuals and undermine hepatitis C prevention efforts. As outlined above, the evidence indicates that people who inject drugs are discriminated against in their access to needles and syringes, because of attitudes towards injecting drug use and the stigma associated with injecting drug use. Health care workers in regional and rural areas stress the resistance to appropriate distribution of needles and syringes through hospitals. One health care worker described the process for accessing needles and syringes at the local hospital. Access is only available through the emergency department, when people go on to the waiting list and are triaged.⁵¹

Discriminatory attitudes towards people who inject drugs encourage resistance to harm reduction measures, this in turn creates an environment in which people are being unnecessarily exposed to the risk of hepatitis C transmission or reinfection.

...contracting HCV necessarily correlates to the *prima facie* existence of widespread discrimination [against people who inject drugs]. The discrimination that follows from acquiring HCV only reinforces and amplifies the discrimination that contributed to the infection in the first instance.⁵²

Numerous submissions stress that the prevailing negative attitudes towards people who inject need to be addressed, both as an end in itself, and to improve the health of people with hepatitis C and to support hepatitis C prevention efforts.

Initiatives to inform or educate relevant service providers and the media about drug use issues, should aim to de-stigmatise people who use or inject drugs.⁵³

It would certainly be my belief that health is a basic right regardless of what behaviour you engage in currently or in the past. We have a criminal system which manages crime. You may not agree with all of its

⁴⁹Dr Ingrid van Beek, Sydney hearing, 2 August 2001.

⁵⁰Health care worker, Dubbo hearing, 16 May 2001.

⁵¹Health care worker, regional hearing, May 2001.

⁵²NUAA, Submission No. 68.

⁵³ANCAHRD, Submission No. 47.

laws but that is the system that we as a society have, so that even if, rightly or wrongly, drug use is criminal, it ought not extend across to affecting people's access to health care. And yet that seems to be the case.⁵⁴

Conclusions and recommendations

Evidence to the Enquiry indicates that the stigma associated with injecting drug use often leads to discrimination against people who have a history of drug use, currently inject drugs or are on drug treatment programs. Such discrimination is widespread and has damaging consequences, both for individuals and for the community. The Enquiry concludes 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 Enquiry recommends that:

- 66. Education initiatives which are designed to address discrimination against people with hepatitis C in employment and health care settings must also examine and challenge stereotypes associated with injecting drugs.**
- 67. The NSW Ministerial Advisory Committee on Hepatitis ensure that the *NSW Hepatitis C Treatment and Care Plan* provides services and programs which are appropriate for and accessible to people who inject drugs and address the specific health care needs of people who are injecting drug users.**
- 68. The NSW Ministerial Advisory Committee on Hepatitis, in conjunction with NSW Health and Area Health Services, develop and implement strategies to improve compliance with NSW Government harm reduction strategies, and improve State and local leadership for harm reduction measures.**
- 69. The NSW Police Service examine and implement strategies to increase compliance with *NSW Police Service guidelines for support of needle and syringe exchange and methadone programs* and provide a report to the NSW Ministerial Advisory Committee on Hepatitis on steps taken to improve compliance.**

The Enquiry endorses the recommendation of the NSW Drug Summit that:

- 70. The NSW Government repeal section 11 of the *Drug Misuse and Trafficking Act 1985* dealing with use or possession of equipment for use in the administration of a prohibited drug.**

3.3 People in custodial institutions

The Enquiry recognises that hepatitis C prevalence among prisoners is high, and that prisoners are particularly vulnerable to infection and reinfection. Many of the difficulties prisoners with hepatitis C face in their access to health care and health promotion services also apply to all prisoners. Given this, the particular experience of prisoners generally, in addition to the experience of prisoners with hepatitis C, has already been the subject of a detailed analysis and recommendations in Chapter 2.

3.4 Aboriginal and Torres Strait Islander People

The vulnerability of Aboriginal and Torres Strait Islander people to hepatitis C infection and their experience of hepatitis C related discrimination needs to be understood within the broader context of race discrimination and systemic disadvantage that affects the lives of many Indigenous people. Evidence to the Enquiry emphasised:

- the disproportionate representation of Indigenous people in the NSW correctional system
- Indigenous people have poor access to primary health care generally
- there is an interrelationship between race discrimination and hepatitis C discrimination
- that there are inadequate or inappropriate hepatitis C education and health services for Indigenous people.

⁵⁴ Dr Ingrid van Beek, Sydney hearing, 2 August 2001.

Health of Indigenous people and access to primary health care

Despite improvements in the health of Indigenous people over the last 20 years, the gap between the health status of Indigenous people compared with non-Indigenous people remains considerable.⁵⁵ The Enquiry notes, for example, estimates indicate that there is higher prevalence of hepatitis B among Indigenous people than among other high risk groups, such as people who inject drugs and gay men.⁵⁶

Evidence to the Enquiry has highlighted the fact that there are many pressing health issues for Indigenous people. Access to hepatitis C treatments needs to be understood within this context.

In terms of Aboriginal people's access to treatment for HCV, that is when the condition gets to the stage where they need interferon or ribavirin or both, the AMS doesn't have a great deal of experience because at this stage there aren't that many Aboriginal people who have been exposed long enough to HCV to require treatment. That partly reflects the fact that Aboriginal people are dying before they develop those complications. We have very few people in their mid-40s that come to our service but basically there aren't that many... ATSI people's expectations of longevity and how they structure their lives around that is quite different [to the non-Indigenous community].⁵⁷

Impact of incarceration

As discussed in detail in Chapter 2, incarceration is recognised as a potent risk factor for hepatitis C infection and reinfection. This has particular consequences for Indigenous people given their over-representation in the correctional system, including juvenile detention centres. While the imprisonment rate for non-Indigenous Australians is 85 per 100,000, for Indigenous Australians it is 1,790 per 100,000.⁵⁸

The high proportion of Indigenous people in the correctional system, the prevalence of hepatitis C among inmates, and the high risk associated with injecting drugs in custodial settings, makes Indigenous people particularly vulnerable to hepatitis C infection. Coupled with the rapid turnover of the prison population, leading to Indigenous people returning to communities, Indigenous health workers expressed fears about the adequacy of hepatitis C prevention in custodial settings and in Indigenous communities.⁵⁹

Aboriginal people have a higher likelihood of living in rural and remote areas and obviously they also have a much higher likelihood of having been in jail at some stage in their lives. So if it's true that NSPs are less commonly found in rural and remote areas and we know that there is extensive needle sharing in jails and juvenile institutions then it's pretty easy to see that there are systemic problems in terms of Aboriginal people's access to services.⁶⁰

Intersection of race and other forms of discrimination

Fear of discrimination and experiences of race discrimination often combine to create a climate of fear that acts as a disincentive to hepatitis C testing, and accessing treatment and prevention information. One Indigenous health worker told the Enquiry about the many challenges she faced in working with young Indigenous women, who often found out about their hepatitis C status when they went into hospital to have a child.

“...the young women I work with, they picked up it up, they know they are being treated badly. They don't know whether it's discrimination about HCV or injecting drug use, or the colour of their skin, but they know they just don't want to be there. So they have often left hospital early, as soon as they can after their baby is born — they don't get the support they need as new mums, don't get enough information about how to prevent HCV transmission, let alone help accessing services for their drug use or HCV.⁶¹”

⁵⁵ *Health is Life — Report on the Inquiry into Indigenous Health*, House of Representatives, Standing Committee on Family and Community Affairs, The Parliament of the Commonwealth of Australia, May 2000, Canberra.

⁵⁶ *HIV/ Viral hepatitis - A guide for primary care*, Australasian Society of HIV Medicine, 2001, Sydney, page 21.

⁵⁷ Dr John Daniels, Redfern AMS, Sydney hearing, 3 August 2001.

⁵⁸ Dolan, K. *Surveillance and prevention of hepatitis C infection in Australian prisons: A discussion paper*, at page 8 and Dr Alex Wodak, Sydney hearing, 2 August 2001.

⁵⁹ Indigenous health worker, regional hearing, May 2001.

⁶⁰ Dr John Daniels, Redfern AMS, Sydney hearing, 3 August 2001.

⁶¹ Indigenous health worker, regional hearing, May 2001.

With the Aboriginal community at the moment, I've found they're not wanting to be tested as much. I've spoken to a couple of women and they've said it's because a few years ago, hep B, when it first came out, all you had to be was Aboriginal and you had hep B. And they think their gonna get another label and that's gonna go on again — they don't want that to happen. There's also a lot of misinformation out there in the Aboriginal community. They think Hep C goes on to HIV and then AIDS. So there's a lot of education happening in the community at the moment...⁶²

Culturally appropriate hepatitis C education resources

Many submissions to the Enquiry have raised concerns about the lack of culturally appropriate educational resources.

A lot of the material around is not Aboriginal-specific and is not culturally appropriate...if they want to target Aboriginal communities...they have to start thinking about little things like the pictures, the colours and there's not a lot around.⁶³

The Enquiry notes that the Hepatitis C Council of NSW is currently working in partnership with the Aboriginal Health and Medical Research Council, Aboriginal Medical Services, Area Health Service Aboriginal health care workers and the Kirketon Road Centre, to develop a basic hepatitis C information pamphlet appropriate for Indigenous communities across NSW. The resource will provide space for local referral information.

Conclusions and recommendations

The Enquiry concludes that Aboriginal and Torres Strait Islander people are particularly vulnerable to hepatitis C infection given the disproportionate representation of Indigenous people in the NSW prison system and the poorer standard of health of Indigenous people generally. Not all hepatitis C related health services are delivered by Aboriginal controlled health services. This underscores the need for mainstream health services to work in partnership with Aboriginal Medical Services to ensure culturally appropriate hepatitis C service delivery and education initiatives.

71. The Enquiry recommends that the following principles should guide the development and delivery of hepatitis C education and services for Aboriginal and Torres Strait Islander people:

- partnerships between mainstream health services and Aboriginal Medical Services should be encouraged
- hepatitis C education initiatives, designed to increase compliance with anti-discrimination law, should incorporate the intersection of hepatitis C discrimination with other forms of discrimination including race discrimination
- education resources and services should be culturally appropriate.

3.5 Culturally and linguistically diverse communities

A number of migrant population groups in Australia are from non-English-speaking countries with relatively high rates of hepatitis C prevalence, in particular through medical procedures such as mass immunisation campaigns. Regions of high hepatitis C prevalence include Asia, the Middle East, Africa, South America, and southern and Eastern Europe. In Egypt, where prevalence is greater than 20% in many areas, a strong association has been found between medical procedures and hepatitis C infection. In Australia, people with hepatitis C who were born in countries with high rates of hepatitis C prevalence appear to have a higher risk of cirrhosis, probably due to longer duration of infection than other risk groups.⁶⁴ Prevalence data for migrant populations in Australia is not available, but it is possible that prevalence may be higher than for the general community.⁶⁵ The Enquiry also notes that estimates indicate that there is higher prevalence of hepatitis B among some culturally and linguistically diverse communities than among other high risk groups,

⁶² Indigenous health worker, regional hearing, May 2001.

⁶³ Indigenous health worker, regional hearing, May 2001.

⁶⁴ Hepatitis C: a management guide for general practitioners, *Australian Family Physician*, December 1999, Vol. 28, page 12.

⁶⁵ *NSW Hepatitis C Strategy*, at page 12.

such as people who inject drugs and gay men.⁶⁶

Evidence to the Enquiry indicates that people from culturally and linguistically diverse communities may experience difficulties in accessing hepatitis C services and programs because of language and cultural barriers.⁶⁷ In the experience of the Multicultural HIV/AIDS Service, fear of breaches of confidentiality and stigmatisation within people's own communities often results in people from culturally and linguistically diverse communities being unwilling to access services.⁶⁸

Hepatitis C affects many ethnic groups in Australia. Cultural beliefs and attitudes, including a reluctance amongst some communities to acknowledge illegal and risk practices, affect how people with hepatitis C are treated. Importantly, real and perceived cultural and linguistic barriers may prevent full access to the health care system, while seeking support from health care providers within their own community may be problematic because of fear of confidentiality being breached, as well as stigmatisation within their community.⁶⁹

I think non-English speaking communities are the most difficult ones to reach because of the taboos and trying to educate the workers from these different communities...is really quite difficult.⁷⁰

Inadequate access to and use of interpreters within the health system not only compromises the quality of health services available to people from culturally and linguistically diverse communities, but also contributes to people's concerns about confidentiality. Evidence indicates that family members and staff within the health agency have been used as interpreters, rather than appropriately qualified interpreters.

Concerns about confidentiality have also been raised when non-qualified staff (receptionist) are used at times to address the language needs of clients from CALD communities. Instead of arranging professional health care interpreters, clients were told 'the service does not have budgets for interpreters'.⁷¹

Recommendation

72. The NSW Ministerial Advisory Committee on Hepatitis ensure that the *NSW Hepatitis C Treatment and Care Plan* provide services, programs and educational resources which are appropriate for and accessible to people from culturally and linguistically diverse communities.

3.6 Young people

Notifications of hepatitis C among people aged 15–19 years have been increasing from less than 100 notifications in 1993 to more than 400 in 1998.⁷² The NSW Hepatitis C Strategy recognises young people as a priority under the strategy, given that early intervention is likely to be highly effective, as studies have shown that the length of injecting drug use is the key predictor of whether a person will become infected with hepatitis C.

Consideration has been given to the importance of school-based hepatitis C education programs and the diversionary programs which take a holistic approach to the needs of young injecting drugs users in contact with the juvenile justice system: see Chapter 2, sections 2.5 and 2.8.

Evidence to the Enquiry highlights the importance of:

- early intervention strategies which aim to reach young injecting drug users
- health care services which work in partnership with youth services to maximise young people's access to health services
- health care services, including needle and syringe programs, being accessible and appropriate for young people.

When [young people] start using they don't have very good skills about using...And then if they do get ill they can't go off to their GP...they don't have Medicare numbers...people are fourteen years old using. I've got people on my books that started at 8 and 9.⁷³

⁶⁶ *HIV/ Viral hepatitis - A guide for primary care*, Australasian Society of HIV Medicine, 2001, Sydney, page 21.

⁶⁷ For example: ANCAHRD HCV Committee, Submission No. 47; and Multicultural HIV/AIDS Service, Submission No. 64.

⁶⁸ Multicultural HIV/AIDS Service, Submission No. 64.

⁶⁹ HCC NSW, Submission No. 80.

⁷⁰ Health care worker, regional hearing, May 2001.

⁷¹ Multicultural HIV/AIDS Service, Submission No. 64.

⁷² *NSW Hepatitis C Strategy*, at page 12.

⁷³ Indigenous health worker, regional hearing, May 2001.

I was talking to a young person the other day who said that when they went to try and get a fit pack from one of the country hospitals they were belittled, made to feel dirty and they had to wait for a long time... a lot of the young people will go to hospitals in other towns rather than go to their own hospital because they may have family members working there or friends of mum or something like that...they're worried about confidentiality.⁷⁴

Evidence to the Enquiry highlights the fact that the young people most vulnerable to hepatitis C may not necessarily benefit from school-based education, as such education, where it occurs, is usually targeted to later years when more marginalised young people are less likely to be in the school system. The health needs of young people should not be limited to holistic responses to drug use when a young person comes into contact with the juvenile justice system.

3.7 Women

Evidence to the Enquiry does not indicate that women with hepatitis C are any more likely to experience discrimination than men with hepatitis C. However, a number of submissions examined women's experiences of discrimination or raised issues of concern that are particular to women with hepatitis C.

Professor Gifford's submission to the Enquiry reported on a recent study she and her colleagues have undertaken about the experience of discrimination among women living with hepatitis C.⁷⁵ The study involving over 600 women and the key findings include:

- 36% of women had their hepatitis C status disclosed without their permission, usually among family and friends
- 48% of women said they had received less favourable treatment from health professionals because of their hepatitis C
- of the women who had a pregnancy (n=174) after being diagnosed with hepatitis C, 9% were advised to have a termination because of their hepatitis C.

The study also found that women who were current or past injecting drug users were more likely to be treated negatively by health professionals than women who never injected:

- dentists 2.1 times more likely
- pharmacists 6.5 times more likely
- nurses 2.4 times more likely.

The Enquiry received numerous submissions regarding discrimination in the provisions of antenatal and post natal care.⁷⁶

Evidence to the Enquiry indicates that breaches of confidentiality, lack of understanding of hepatitis C transmission and poor implementation of standard infection control procedures are common in maternity wards. This often had profound effects upon the women concerned, both emotionally and in terms of the quality of care provided. Some examples have been considered in Chapter 2, section 2.3.

A pregnant woman called the Hepatitis C Helpline, extremely distressed, sobbing. Her antenatal blood tests revealed that she was HCV positive. She had been informed that HCV is sexually transmitted 'so my partner has it' and also that HCV is inevitably transmitted from mother to baby 'so both my children and this baby have it too and I gave it to them...This woman reported suicidal ideation.⁷⁷

When I was in hospital with my daughter, they wouldn't let her near me...I wasn't allowed to breastfeed her, I wasn't allowed to have her in bed with me...It was like, 'keep away from the baby, you'll disease her'.⁷⁸

case study

Two weeks before my son was born...the doctor was filling out the appropriate forms which included a question about HCV status. I said yes [I had HCV]...I went on to explain that although I had HCV, I have accessed treatment and had remained PCR negative for the previous three years, therefore, I was no threat in terms of transmission to her staff. Notwithstanding this, the hospital should follow universal precautions. She said she wanted to confirm the PCR result, which I was quite happy to comply with, but I explained that the result will take a month and my son was due in two weeks, therefore, it was not likely to be of any benefit to them.

The following week I returned and further discussion took place because virtually the entire antenatal staff including doctors and nurses had held an emergency meeting to discuss my positive HCV status...considering that at this point I was ready to give birth I was really traumatised by this whole situation and, considering that I'm quite an assertive person I can only imagine what that would have been like for a person who was less well educated and informed...[this kind of treatment] infringes on what should be an extremely positive experience.⁷⁹

⁷⁴Health care worker, regional hearing, May 2001.

⁷⁵Gifford, S., O'Brien, M., Banwell, C. and Bammer, G. 2001 *Survey of women living with hepatitis C in Victoria and ACT*; Professor Sandy Gifford, Submission No. 94 — Experience of discrimination among women living with hepatitis C.

⁷⁶In addition to examples cited here and in Chapter 2, see also Individual Submissions No. 30 and No. 95.

⁷⁷Hepatitis C Helpline (Victoria), Submission No. 54.

⁷⁸Individual Submission, regional hearing, May 2001.

⁷⁹Individual Submission No. 28.

3.8 People living in regional and rural communities

Access to health care

Evidence to the Enquiry indicates that people with HCV who live in regional and rural areas experience particular difficulties in accessing appropriate HCV health care.

In all the regional hearings of the Enquiry people raised concerns about the fact that there are fewer and fewer GPs in rural and regional areas, particularly GPs that bulk bill.

A lot of other rural areas have this issue as well, there's a lack of bulk billing GPs. So people put off going to the doctor because they have to pay — they'll wait till they're really quite ill... There's a number of GPs in [our area] that don't even bulk bill health care card holders. They will bulk bill pensioners, but for people with a health care card, they charge them as well.

In this town it takes sometimes a week or more to get an appointment with a GP and in the smaller outlying towns it might take three weeks to get in to have a normal GP visit. Those sorts of issues make it difficult for people to do things like follow up on tests and then get results.⁸⁰

Many submissions raise concerns about access to appropriate health care in regional and rural areas. It is more viable in metropolitan areas for people with hepatitis C to shop around for health care professionals with appropriate levels of expertise and with whom they feel comfortable. Obviously it is much more difficult to do this in regional and rural areas where health care services are more limited, particularly access to GPs.

My experiences in rural NSW with GPs were terrible. I have found I know much more about the disease than any GP I have ever met... It is ignorance which breeds fear and discrimination, and the best way to counter it is through regularly updated education of healthcare workers, including management and governance levels, and the wider community.⁸¹

While some of the issues raised in evidence to the Enquiry relate particularly to access to hepatitis C specialists and combination therapies, there are also underlying issues about access to health care for rural and regional communities more generally. Clearly these issues impact upon people who have hepatitis C. However, the broader issues about access to health care in regional and

rural areas generally are also the subject of a detailed analysis by the NSW Ministerial Advisory Committee on Health Services in smaller towns.⁸³ Enhancing services to rural communities is also integral to the work of the NSW Health Council.⁸⁴

case study

'I went to a new GP in a small town, I told him I had hepatitis C probably for 10 years. I felt a change in his approach to me... he asked me how did I get hepatitis C... I paused thinking how I answer this question is going to affect how I get treated by the only doctor in this tiny town.'

The woman states that she had answered the GP's question honestly. Subsequently, she experienced four years of regular and acute episodes of excruciating abdominal pain. This pain went undiagnosed and untreated because every time she presented to her GP reporting the intense pain she was 'fobbed off'. The local Emergency staff were told by the GP that she was a 'former IV drug user just shopping for Pethidine'. Finally this person presented at the Emergency department in obvious agony and the locum in attendance acknowledged that her pain was real and sought to relieve and diagnose it. The subsequent tests revealed extensive intestinal polyps. Subsequent appropriate treatment meant this person has not experienced the abdominal pain since.⁸²

⁸⁰ Health care workers, regional hearing, May 2001.

⁸¹ Individual Submission No. 15.

⁸² Hepatitis C Helpline (Victoria), Submission No. 54.

⁸³ *Report to NSW Minister for Health: Framework for Change*, NSW Ministerial Advisory Committee on Health Services in Smaller Towns, NSW Government, February 2000.

⁸⁴ *Report of the NSW Health Council: A Better Health System for NSW*, NSW Government, March 2000.

Confidentiality

Another theme which emerges strongly from evidence to the Enquiry is fear of disclosure and breaches of confidentiality in smaller communities. In the experience of the Hepatitis C Council of NSW, some of the most serious cases of discrimination and vilification occur when it becomes generally known in a small country town or rural community that a person has hepatitis C.⁸⁵ In small communities the disclosure of an individual's health status can often lead to public identification. Any consequent discrimination can limit a person's participation in the community, limit their employment opportunities, and affect the provision of goods and services, including health care.

This often results in people with hepatitis C being particularly loath to disclose their hepatitis C status, resulting in people with hepatitis C being particularly isolated. This in turn affects their capacity to access the necessary health care services to enable them to monitor their health and have treatment.

Experiences of social isolation can be exacerbated by the lack of specific hepatitis C health care services or advocacy and support groups in rural, regional and remote areas.

I think people are very jumpy about the level of confidentiality that is achievable... it's the country town thing.

And there is a reasonable amount of discrimination amongst the smaller towns — anonymity and confidentiality can be a bit difficult in smaller towns.

I'd get questions like 'Are there people who are ex-users? Well, where are they? Who are they?' We live in a society where people cannot say openly that they are ex-users and my experience in regional areas is that it's even harder.⁸⁶

3.9 Medically acquired hepatitis C

The *NSW Hepatitis C Strategy* states that people with medically acquired hepatitis C, including through blood transfusion and people with haemophilia, are thought to comprise the second highest number of prevalence cases after people who inject drugs. Since 1990 all blood has been screened for hepatitis C and the risk of transmission through blood transfusions in Australia is now very low.⁸⁷ As a result most people who acquired hepatitis C through a medical procedure will have been infected over 10 years ago.

Evidence to the Enquiry does not indicate that the discrimination experienced by people who acquired hepatitis C through medical procedures is any different from the experience of people who acquired hepatitis C by other means. Most people with hepatitis C are assumed to be injecting drug users regardless of their mode of infection, or whether they have not used drugs for many years. For all people with hepatitis C this association is problematic because of widespread negative attitudes towards injecting drug use. Thus, people with hepatitis C, regardless of the mode of transmission, experience discrimination on the basis of their hepatitis C status and on the basis of past, current or assumed injecting drug use. This has been considered in detail in Chapter 2.

It is worth noting a number of salient issues about the prejudice attached to injecting drug use as the mode of transmission and the consequences, which can flow from that.

For example, many individual oral and written submissions to the Enquiry felt the need to state that they had acquired hepatitis C as a result of blood transfusion prior to 1990. This is also the experience of hepatitis C organisations. Others stated that they were concerned about drawing attention to the fact that they acquired hepatitis C through a blood transfusion for fear of perpetuating the 'guilty and innocent' dichotomy.

People go to great lengths to explain to Helpline workers that they did not contract hepatitis C from injecting drug use, suggesting that stigma and discrimination associated with hepatitis C often come from the mode of transmission rather than the virus itself.⁸⁸

Some submissions raised concerns about the degree to which people who became infected through injecting drug use were seen as less deserving of support and assistance.

⁸⁵ HCC NSW, Submission No. 80.

⁸⁶ Health care workers, regional hearing, May 2001.

⁸⁷ *NSW Hepatitis C Strategy* at page 5.

⁸⁸ HCC NSW, Submission No. 80.

Some support groups are only for those who contracted the disease through a blood transfusion: 'the support group was only for those who contracted the disease through blood transfusion and that people who contracted it through drug use were not really welcome'.⁸⁹

The form of prejudice I find the most hurtful is what I will call the fault/no fault divide. A number of people I have chosen to tell about my illness have asked how I contracted it. When I told them I believe I got it through sharing injecting equipment 16 years ago they responded by saying 'Oh, I know someone else who has hep C, but they got it through a needle stick injury/blood transfusion/from a sexual partner'. In other words, their illness is not their fault. They are innocent 'victims'. I find this response to my individual situation absolutely offensive. I also believe that for the people who have responded to me in this way, the fact that once upon a time I used heroin is a defining piece of information. They see me differently to the way they used to and treat me accordingly.⁹⁰

The NCHSR's social analysis of evidence to the Enquiry examines the distinction between 'guilty' and 'innocent' victims.

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.⁹¹

As has been explored earlier in this chapter, discrimination against people who inject illicit drugs has damaging consequences for the health of people who inject drugs and for hepatitis C prevention efforts.

⁸⁹ Individual Submission No. 4.

⁹⁰ Individual Submission No. 46.

⁹¹ NCHSR social analysis of evidence to the Enquiry: see Appendix E.