Report of the enquiry into hepatitis C related discrimination
In the course of human history there is always change. Some times the changes are small, incremental, predictable, almost unnoticeable; sometimes they are vast, unexpected, and herald great transformations. The latter are 'sea-changes'.

In calling our report into hepatitis C related discrimination C-change, what we are essentially calling for is a major transformation in public policy — one which refuses to accept that discrimination is the inevitable companion of hepatitis C infection and one which asserts that the level of hepatitis C related discrimination which this Enquiry has identified cannot be tolerated any longer.

Concepts of health and illness, well-being and disease are cultural constructs — they vary with time and place, with ideology and belief. Over the course of history our views about health and illness have changed. We have moved, or so most of us would like to believe, away from a paradigm where the causes of illness, being unknown, were ascribed to divine judgement or intervention, to a paradigm where we have started to understand the biological, physical and psychosocial origins of our personal and community maladies.

However, every now and again, along comes some new infection, some new threat to public and personal health, something where the origins are initially uncertain and obscure. In such circumstances it often appears that it does not take long for us to revert to a more primitive reaction to these new challenges and, in particular, for us to exhibit an irrational degree of prejudice and discrimination against those who suffer from the new infection. This is particularly manifest when the new infection is somehow linked with aspects of personal behaviour which depart from the prevailing contemporary norm.

This was first evidenced in the reaction in western societies to the appearance of certain sexually transmitted infections in the fifteenth century.1 It made an interesting appearance in Sydney at the turn of the last century when an outbreak of the bubonic plague in that city led to an outburst of hysterical over-reactions, many of them aimed directly at the city's Chinese community.2 Most recently it has been exposed in terms of reactions to the appearance of HIV/AIDS.3

In 1992, the Anti-Discrimination Board conducted an enquiry into HIV and AIDS related discrimination. In its report, entitled Discrimination — the Other Epidemic, the Board stated:

"Australia has a proud reputation as a nation in which all people receive a fair go. However the impact of HIV and AIDS has severely challenged that tradition. Many people in our community do not receive a fair go. They have been subject to prejudice, discrimination, vilification and even violence because they are infected with HIV, or because it is assumed they are infected. Some of them have been forced out of their employment and accommodation; some have been denied basic health care. Their rights to privacy and confidentiality have been almost routinely violated…For many people, HIV and AIDS related prejudice and discrimination are so extensive that they simply accept them as part of life, feeling powerless to do anything about them.4"

Readers of this Report will find that analysis depressingly familiar — a mere substitution of hepatitis C for HIV and AIDS will suffice to show how little has changed and how much still needs to be done.

In relation to a key issue in the discussion of what motivates hepatitis C related discrimination we must address the social constructs of drug use and abuse. As with social constructs of health and illness, community attitudes towards drug use change over time.5

Sir Arthur Conan Doyle could write eloquently about Sherlock Holmes making decisions about which syringes he would use to inject which drugs of which particular strength and potency without his Victorian audiences demurring. Notable poets and authors of that era extolled the virtues of a variety of now illegal activities.

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5 An excellent analysis of this in relation to both licit and illicit drugs is to be found in Senate Standing Committee on Social Welfare 1977 Drug problems in Australia — an intoxicated society? AGPS, Canberra.
substances. A great Prime Minister like Gladstone would regularly resort to a small dose of laudanum (a tincture of opium) to see him through his daily routine, while the famous social reformer William Wilberforce carried out all his great works, such as leading the crusade to abolish the slave trade, despite a 45 year addiction to opium. The British Empire even went to war against China to prevent its government from suppressing the opium trade. Such drug taking today is both criminalised by the law and demonised by politicians.

By contrast, King James I could write A Counterblast to Tobacco denouncing its moral and physical vices, and he undertook vigorous steps to prohibit its use, whereas today governments depend upon it as a source of revenue and politicians accept tobacco company hospitality at sporting events.

The political history of cannabis use demonstrates how factors such as racial discrimination have been crucial in developing public policy towards the use of some substances, once commonplace, now criminalised.

In other words, views about what constitutes illicit drug taking behaviour vary over time and with shifts in government policy. Despite the fact that tobacco constitutes the greatest single threat to public health in Australia and causes infinitely more deaths and suffering than the use of illicit substances, it remains legal. Similarly it is worth noting that all major reports into the legal, social and economic costs of illicit drug use in Australia have called for major legislative reforms in this area.

The illegal status of much of this drug use finds expression in terms of negative health outcomes for many people with hepatitis C. This Report shows clearly that the perception of people with hepatitis C as somehow deviant and automatically engaged in illegal or criminal behaviour lies at the root of internalised justifications for treating people in a discriminatory fashion. Were this nexus to be severed, either by means of legislative change or by changes in perceptions, attitudes and responses, then most of the problems identified in this Report would be more easily resolved.

If issues such as what constitutes health or what substances are regarded as illicit are so dependent upon changing cultural and historical circumstances, can we not anticipate that it is genuinely possible to break the nexus between certain types of ill health and the discrimination which accompanies them?

In this Report we assert that such changes can occur and we offer what we think are practical suggestions for promoting those changes.

Most of our suggestions revolve around the concept of better community and professional education. We believe that increasing awareness of what hepatitis C is, how it is contracted and who contracts it, will go a long way to breaking down the stereotypes which lead to prejudice and discrimination. This in turn will improve health outcomes for both individuals and the community in general.

However we also believe that governments have an important role to play. Again, the history of HIV is instructive. To create the ‘enabling environment’ in which each of the Australian National Strategies in relation to HIV/AIDS have flourished required legislative action on the part of governments — in particular the repeal of laws which discriminated against homosexuals. What this law reform did was to send out a clear public signal that a particular type of discrimination was no longer acceptable and was formally rejected by those charged with national and State leadership in the making of laws and public policy. In this respect, law reform underpinned the great thesis of Martin Luther King that laws against discrimination cannot change the hearts of men but they can restrain the behaviour of the heartless.

Throughout this Report we have attempted to develop practical solutions and recommendations which can be adopted by government, service providers, community organisations, professional associations and individuals. In relation to those recommendations addressed to government or public sector agencies, the Anti-Discrimination Board will be following up over time to see to what extent they have been acted upon and with what commitment and success.

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‘(1604) ‘A custom loathsome to the eye, hateful to the nose, harmful to the brain, dangerous to the lungs, and in the black stinking fume thereof, nearest resembling the horrible Stygian smoke of the pit that is bottomless.’


C-change is the product of a great deal of work by many people. On behalf of the Anti-Discrimination Board I would like to thank all of those people who contributed. The many individuals who presented submissions either in writing or in person gave this Enquiry its unique insight and flavour. The members of the Statutory Board who sat throughout the Enquiry, and contributed their time and expertise, were most capably supported by numerous officers of that Board. The efforts of the members of the Steering Committee who provided ongoing advice and counsel are much appreciated. So indeed is the support of the Attorney General, Hon Bob Debus MP and the Director General of his Department, Mr Laurie Glanfield AM who provided the funding for our work to take place. Most of all, however, our thanks go to Julia Cabassi who heroically guided this enquiry, shaped its operations and effectively wrote the final Report — her effort has been monumental.

At the end of the day this Report is a clarion call for a sea change to take place, or rather for many of them to take place. They must take place in our understanding of the origins, natural history and transmission of what is simply another virus. They must take place in our willingness to discuss openly questions of personal behaviour and health outcomes. They must take place in our education systems, from kindergartens to learned colleges. They must take place in our legislative arrangements, in our courts and in policing and custodial practices. Above all, however, they must take place in the ways in which we respond to and treat each other, in the ways in which we extend respect to our fellows and recognise ourselves in them.

Unlawful and unjustified discrimination is a hallmark of ignorance and illustrates a lack of moral decency. We should perhaps remember that great teaching “inasmuch as you have done it to one of these, the least of my brethren, you have done it unto me.”13 We could, any one of us, be there.

Chris Puplick
President

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13 Matthew 25:40
Case study

I've been living with hepatitis C for about 17 years, but I only found out about it in March last year. And the way I found out about it wasn't that great. I'd been feeling very unwell, on and off for probably about six years. I do a fairly high pressure job and I'd just get really run down and go to the doctor and they'd say, 'Oh you've had some sort of virus — have a couple of days off work — back you go', and back I would go…finally by February last year, I'd got to the point where I couldn't get out of bed in the morning…I'd been telling my doctor for a good six months before my diagnosis about my symptoms and she just kept saying, 'You'll be alright, you've just had a virus'.

So finally, I knew I just couldn't keep going and I went back to her and asked her if she would run some blood tests, which she did. They came back and my LFTs [liver function tests] were elevated…this took my mind back to 1985 — I'd been using heroin, I wasn't very well. I had a fantastic GP at the time. But of course, hepatitis C wasn't known about back then, so she kept running these tests and saying 'You haven't got hepatitis A, you haven't got hepatitis B, but you have some kind of hepatitis'. So my mind immediately went back to then.

So I asked this doctor if she would run some more tests and I asked specifically if she would run a hepatitis C test. She said, 'You wouldn't have that'. And it was really difficult for me, but I had to say, 'Actually, I think it is possible that I may have that, because I'd been an intravenous drug user 15 years earlier'. And her head just went down and she didn't say anything. Then she said, 'Okay, we'll order the test'. A week later, she calls me in, and she said, 'I've got some very bad news…you have hepatitis C', which was a terrible shock…I started to cry and she didn't have a tissue in the room so she kind of got up and left the room for a couple of minutes and she came back with one tissue and a little brochure that had been produced in 1991.

I had quite a lot of questions — I felt so sick, I didn't want to feel the way I was feeling. So I started to ask some questions about what could be done…she just looked at me and said, 'I'm sorry but I really can't tell you anything about it because I don't see hepatitis C in my surgery'. I pulled myself together a bit more and I kept trying to ask questions…I sat there for a little bit longer and said, 'Surely there's something that can be done about this'. And so she kind of pfaffed around and found a medical directory and she said, 'Oh I think maybe there's a clinic at the Nepean Hospital'. She made a phone call and she said, 'They probably just want you to go in for liver biopsy'. And that was the end of the session.

I walked out, I was dreadfully upset. I've got the tissue — I'm trying to hide the brochure to get out of the crowded waiting room and I got home and read the brochure — which I'm sure in 1991 was probably a very good document, but it scared the be-jesus out of me, because it basically presented a fairly grim prognosis for people with hep C…the information wasn't up to date at all…so I spent the entire day feeling incredibly distraught.
But I was lucky — it was the 27th of March 2000 and it was the day the NSW Government launched its education campaign on hep C, so the gods were smiling on me. I’m sitting there tear-stained, feeling so sick and this wonderful, wonderful news item came on that told me all about hepatitis C, told me that there were treatments available, showed me that there were other people living with this disease. And also that there were people that had been treated in a very similar manner to the way I had, speaking about their experiences of discrimination. So that cheered me up too — I thought, ‘Oh well, I’m not the only person that’s being treated like a little bit of scum’.

I got in touch with the hospital and they were fantastic — they took me in, they gave me a lot of support. They gave me a list of GPs in my local area that would be prepared to treat me and not dismiss me in the way my own doctor had. But it still took me a good few months to shift my feelings of self-loathing and blaming myself for the situation I was in…it’s been a real struggle.

In the relatively short time that I’ve known about my illness, I’ve come across a lot of other people that have hepatitis C who have similar stories. I think the thing that upsets me the most is this kind of shame and blame stuff that goes on with hepatitis C. In my support group at the hospital — people will often express the sentiment that their illness is some kind of payment for their sins. I think that’s terrible, because I think that means that people have such an appalling image of themselves that they’re going to be prepared to put up with some really shabby treatment from other people. They expect other people to think less of them, not to have any compassion for their situation. They’re terribly frightened of anyone finding out and judging them. It’s a really terrible situation.

The fear of being discriminated against is incredibly powerful. It really makes you feel like you’re so alone with your illness. I think there’s very good reasons why people don’t want to disclose the fact that they have hepatitis C and no doubt this Enquiry has heard many examples — so the fear is real. But I think it’s a very important thing that people can overcome that a little bit because you need support when you’re ill. It’s very difficult not to disclose your illness when you can’t walk properly. I’d sort of try and get out from my desk and people would say, ‘Why are you limping? Why are you so pale and puffy looking? Why have you got your head down on your desk after lunch?’ It’s very difficult if you’re trying to get on with your life not to tell people. I’ve had some bad experiences with people’s attitudes to hepatitis C, but I’ve found that since I have been able to feel a little bit braver and disclose more about my illness, that I’ve actually had a lot of positive feedback and a lot of support from people that I think I otherwise wouldn’t have had. So I think that that silence that surrounds hepatitis C can be a real burden.

And I think that people living with hepatitis C perhaps are in a position to change people’s attitudes and to make a contribution to fighting this discrimination ourselves…It would just be nice to think that attitudes have shifted enough for people to be able to summon the courage to be able to do that.¹

¹Individual oral submission, Sydney hearing, 2 August 2001.
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Terms of reference

The terms of reference for the Anti-Discrimination Board’s Enquiry into Hepatitis C Related Discrimination are to investigate the extent and nature of discrimination against people who have, or are thought to have, hepatitis C in New South Wales and to make recommendations for combating and eliminating this discrimination and its effects.

List of abbreviations

ACON — AIDS Council of NSW
ADA — Anti-Discrimination Act 1977 (NSW)
ADB — Anti-Discrimination Board of NSW
ADT — Administrative Decisions Tribunal
AHC — Australian Hepatitis Council
AHS — Area Health Service
AIDS — acquired immunodeficiency syndrome
AIVL — Australian Intravenous League
AMS — Aboriginal Medical Service
ANCAHRD — Australian National Council on AIDS, Hepatitis C and Related Diseases
ARCSHS — Australian Research Centre in Sex Health and Society
ASHM — Australasian Society for HIV Medicine
CDHAC — Commonwealth Department of Health and Aged Care
CHS — Corrections Health Service
DCS — Department of Corrective Services
DDA — Disability Discrimination Act 1992 (Commonwealth)
GPs — general practitioners
HALC — HIV/AIDS Legal Centre
HCC Act — Health Care Complaints Act 1993
HCC NSW — Hepatitis C Council of NSW
HCCC — Health Care Complaints Commission
HCV — hepatitis C virus
HCWs — health care workers
HIV — human immunodeficiency virus
HREOC — Human Rights and Equal Opportunity Commission
IRA — Industrial Relations Act 1996 (NSW)
IRC — Industrial Relations Commission
IDU — injecting drug user/user
IFSA — Investment and Financial Services Association
IPPs — Information Protection Principles
LFT — liver function test
LRC — Law Reform Commission
NCHECR — National Centre in HIV Epidemiology and Clinical Research
NCHSR — National Centre in HIV Social Research
NDARC — National Drug and Alcohol Research Centre
NSPs — needle and syringe programs
NSW DET — NSW Department of Education and Training
NSW Health — NSW Department of Health
NUAA — NSW Users and AIDS Association
PBS — Pharmaceutical Benefits Scheme
PCR — polymerase chain reaction test
PHA — Public Health Act 1991 (NSW)
PHR — Public Health Regulations 1991 (NSW)
PPIP Act — The Privacy and Personal Information Protection Act 1998 (NSW)
OH&S — occupational health and safety
SWOP — Sex Workers Outreach Project
Executive summary

Report of the enquiry into hepatitis C related discrimination

ANTI-DISCRIMINATION BOARD OF NEW SOUTH WALES
Executive Summary

Key conclusions

The evidence to this Enquiry clearly demonstrates that hepatitis C is a highly stigmatised condition and that discrimination against people with hepatitis C is rife. Such discrimination is often driven by irrational fears about hepatitis C infection, due to an inadequate understanding of how hepatitis C is transmitted. However, a perhaps more powerful driving force for discrimination than ignorance about hepatitis C transmission, is that infection is inextricably linked with illicit drug use, a highly stigmatised behaviour. Evidence to this Enquiry makes it abundantly clear that discrimination against people with hepatitis C is often motivated by stereotyped responses towards people on the basis of past, current or assumed injecting drug use.

Hepatitis C related discrimination takes many forms and occurs in many areas of public life. It is apparent from the evidence that hepatitis C related discrimination in health care settings is widespread and discrimination in employment is also commonplace. The Enquiry has heard a wide range of examples of discrimination experienced by people with hepatitis C, such as people being rejected by family and friends, ostracised in workplaces and communities, denied life insurance, and terminated from employment. So too, family and friends have been denied the right to view the body of a person known or assumed to be hepatitis C positive.

Discrimination often has a profound impact on the lives of people with hepatitis C; it frequently has damaging health, financial, social and emotional consequences both for people living with hepatitis C and for the community. The experience of discrimination acts as a deterrent to people accessing the health system, with all the consequences this brings for the health of people with hepatitis C and the community.

Specific conclusions and recommendations

Health care settings

Health care settings were the most commonly reported context for hepatitis C discrimination. Evidence to this Enquiry demonstrates that hepatitis C related discrimination in health care settings is widespread and has significant ramifications for the health and well-being of people with hepatitis C. Such discrimination undermines the relationship between people with hepatitis C and health care professionals, and can become a serious deterrent for people seeking health care. In order to effectively address hepatitis C related discrimination in health care settings a range of policy, legislative and educational responses are necessary.

Hepatitis C testing

The Enquiry recommends that:

1. The Public Health Act 1991 (NSW) is amended to provide that hepatitis C testing of individuals is only carried out with their informed consent, except in specific cases of mandatory and compulsory testing authorised by law.

2. NSW Health, in consultation with the Ministerial Advisory Committee on Hepatitis, develop a comprehensive hepatitis C testing circular, in line with the National Hepatitis C Testing Policy, outlining that hepatitis C testing should only occur with informed consent and accompanied by appropriate pre-test information and post test counselling.

3. NSW Health disseminate the hepatitis C testing circular to all Area Health Services for implementation in health care services within their jurisdiction.

4. Area Health Services report to NSW Health on steps taken to implement the hepatitis C testing circular within 12 months of the circular’s release.

5. The Ministerial Advisory Committee on Hepatitis and NSW Health disseminate and promote the hepatitis C testing circular to private sector health providers, in particular GPs, through the NSW office of...
the Royal Australian College of General Practitioners and the Divisions of General Practice in NSW.

6. The Ministerial Advisory Committee on Hepatitis consider mechanisms for ensuring provision of appropriate information to doctors and people with hepatitis C upon provision by pathology laboratories of a positive hepatitis C test result, in addition to the education strategies outlined elsewhere in this report.

Confidentiality and privacy
The Enquiry recommends that:

7. Section 17 of the Public Health Act 1991 (NSW) is amended to include hepatitis C and thereby provide a specific confidentiality provision in relation to non-disclosure of a person’s hepatitis C status in the same terms the Public Health Act currently provides in relation to HIV.

8. NSW Health, in consultation with the Ministerial Advisory Committee on Hepatitis, develop a circular which provides clear guidelines on legal requirements in relation to hepatitis C and confidentiality.

9. NSW Health disseminate the circular on hepatitis C and confidentiality to all Area Health Services for implementation in health care services within their jurisdiction.

10. The Ministerial Advisory Committee on Hepatitis and NSW Health disseminate and promote the circular on hepatitis C and confidentiality to private sector health providers, in particular GPs.

11. NSW Health revise its Privacy Code of Practice 1998 to include hepatitis C within the list of ‘special information categories’.

12. Area Health Services take all necessary steps to promote compliance with privacy legislation and the Privacy Code of Practice 1998 within their health care facilities.

13. Area Health Services provide a report to NSW Health, within 12 months of the circular’s release, on steps taken to:
   - promote compliance with privacy legislation and the Privacy Code of Practice 1998
   - ensure implementation of the circular on hepatitis C and confidentiality.

Infection control
The Enquiry concludes that there is an urgent need to improve the implementation of standard infection control procedures, particularly in hospitals and dental surgeries. Continuing education is essential to reduce discrimination in health services and ensure the safety of both patients and health care workers.

The Enquiry recommends that:

14. Area Health Services ensure that:
   - hepatitis C education for health care workers includes standard infection control procedures, and assesses health care workers’ knowledge of such procedures and their understanding of the rationale for standard infection control procedures
   - all health services within their jurisdiction have in place standard infection control procedures appropriate to their health setting and that the implementation of standard infection control procedures occurs in the context of existing quality assurance systems at service level.

15. The Australian Dental Association (NSW Branch):
   - undertake ongoing education concerning standard infection control procedures that incorporates the rationale for such procedures
   - ensure that implementation of standard infection control procedures is adequately monitored
   - link adequate systems for monitoring standard infection control procedures to the accreditation of dental workplaces.

Access to hepatitis C treatment
The Enquiry recommends that:

16. The NSW Ministerial Advisory Committee on Hepatitis consider and determine appropriate strategies to improve access to best practice therapy for people who currently inject drugs.

17. The NSW Ministerial Advisory Committee on Hepatitis consider and determine appropriate strategies to improve access to best practice therapy for people living in regional and rural communities.
Education and training

The Enquiry recommends that:

18. NSW Health, in conjunction with Area Health Services, ensure that health care worker hepatitis C education and training forms an integral part of Area Health Services’ hepatitis C Strategies/Service Planning.

19. NSW Health ensure that adequate funding is made available to Area Health Services to address the hepatitis C education and training needs of all health care workers.

20. Area Health Services allocate adequate resources for hepatitis C education, training and workforce development that encourages continuous learning, is integrated within management systems and linked to organisational strategic outcomes.

21. Area Health Services provide hepatitis C education, training and workforce development for health care workers that:
   - enables health care workers to examine their values, attitudes, stereotypes and myths associated with hepatitis C transmission, people with hepatitis C and people who have injected or do inject drugs
   - supports implementation of standard infection control procedures and confidentiality policies and procedures
   - ensures health care workers understand and comply with their obligations under anti-discrimination, privacy and related legislation.

22. The National Review of Nursing Education examine existing opportunities for continuing professional education about hepatitis C for nurses and consider options for improving such opportunities.

23. The Ministerial Advisory Committee on Hepatitis ensure that the NSW Hepatitis C Treatment and Care Plan provides minimum standards for Area Health Services in the delivery of appropriate hepatitis C education, training and workforce development for all health care workers.

24. The following principles should guide the development and delivery of hepatitis C education and training for GPs. Education initiatives should:
   - provide GPs with the opportunity to examine the values, attitudes, stereotypes and myths associated with hepatitis C transmission, people with hepatitis C, and people who have injected or do inject drugs
   - include information about GPs’ obligations under anti-discrimination, privacy and related legislation
   - assist GPs to implement non-discriminatory policies and practices, including standard infection control and confidentiality policies, which support compliance with anti-discrimination and privacy legislation
   - integrate hepatitis C education with related disciplines
   - actively involve GPs, people with hepatitis C and those affected by hepatitis C in design and delivery.

25. Pre-service tertiary training and educational institutions develop and incorporate hepatitis C specific education, including a focus on anti-discrimination, into their curricula for people training as nurses, doctors, dentists and other health care professionals.

Employment

Submissions made to the Enquiry indicate that hepatitis C related discrimination in employment is the most common setting for discrimination, after health care settings. The Enquiry concludes that hepatitis C related discrimination in employment is extensive and takes many forms, including selection and recruitment practices which deter people from seeking employment, loss of employment and harassment in the workplace. Such discrimination often has devastating financial, social and emotional consequences.

It is clear that many employers do not understand their obligations under anti-discrimination law. Evidence indicates that many employers have an inadequate knowledge of hepatitis C transmission, the extent to which it is a risk in the workplace, and the rationale for standard infection control procedures. Hepatitis C education initiatives targeting key private and public sector employers are essential in order to address hepatitis C related discrimination in employment.
The Enquiry recommends that:

26. The WorkCover Authority of NSW update and reissue the *Code of Practice: HIV and other blood-borne pathogens in the workplace*.

27. The ADB establish an advisory committee to develop and deliver a Hepatitis C Workplace Education Strategy to ensure an effective and coordinated response to hepatitis C related discrimination in employment. The advisory committee should include representatives from the NSW WorkCover Authority, NSW Health, the NSW Labor Council, Privacy NSW, and relevant community, employer and union representatives.

28. The Hepatitis C Workplace Education Strategy should include activities that support and promote:
   - effective implementation of appropriate workplace policies in relation to non-discriminatory selection and recruitment, in compliance with anti-discrimination law
   - adequate and appropriate workplace training regarding the rights and obligations of employers and employees under anti-discrimination law
   - effective implementation of appropriate workplace policies in relation to infection control, in compliance with the WorkCover Authority of NSW’s *Code of Practice: HIV and other blood-borne pathogens in the workplace*, as updated, and OH&S law
   - effective implementation of workplace policies on confidentiality and privacy, in compliance with privacy laws.

29. The NSW Government provide adequate funds for the development and implementation of the Hepatitis C Workplace Education Strategy.

30. The NSW Government amend the ADA to include discrimination on the ground of profession, trade, occupation or calling.

**Custodial settings**

People in custodial settings should have access to health care services and programs of a standard equivalent to that available in the community. While evidence to the Enquiry indicates that discrimination on the basis of inmates’ hepatitis C status does occur, the most pressing concerns raised are in relation to access to health care, health promotion and hepatitis C prevention programs and services for prisoners, regardless of whether they have hepatitis C. Impediments to the effective delivery of health care and health promotion services in custodial settings have significant and detrimental consequences for the health of all prisoners, including many hepatitis C positive inmates in the NSW correctional system.

**Access to health care**

The Enquiry recommends that:

31. NSW Health recognise the importance of the integration of health promotion and hepatitis C prevention within the clinical service delivery provided by the CHS, and ensure that the health promotion and hepatitis C prevention services provided by the CHS are adequately funded.

32. NSW Health ensure adequate resources are provided for the capacity building necessary to enable the effective implementation of the CHS hepatitis C continuum of care, including implementation of specific protocols incorporating health promotion, prevention, services for newly diagnosed inmates, ongoing clinical management and discharge planning.

33. The DCS and the CHS develop and implement protocols to enable effective discharge planning to maximise prisoners’ access to health services post release.

34. NSW Health, in conjunction with the CHS, other relevant Area Health Services and the DCS, develop service protocols to improve prisoners’ access to hospitals for day-only procedures and agreed mechanisms for linking prisoners into health services in the community, post release.

35. The NSW Ministerial Advisory Committee on Hepatitis give consideration to the emerging scientific literature that indicates that liver biopsy may not be mandatory in order to determine whether treatment is indicated and, if appropriate, enable the use of serological markers to assess liver damage, in order to maximise inmates’ access to hepatitis C treatment.

36. The DCS provide the NSW Ministerial Advisory Committee on Hepatitis with the report arising from the review of the Alcohol and Other Drugs and HIV Health Promotion Units and updated information
as requested by the Committee to enable the Committee to examine whether the health promotion and hepatitis C prevention education services and programs provided by the DCS are adequate to meet demand.

37. The DCS evaluate the currency of information in the HIV/AIDS communicable diseases and health promotion policies and procedures, particularly the coverage of hepatitis C, and the extent to which these policies and procedures reflect current practice.

38. The DCS update the HIV/AIDS communicable diseases and health promotion policies and procedures, in line with the review and evaluation findings.

39. The DCS ensure the effective implementation of revised policies and procedures, with particular emphasis on education and training in relation to standard infection control procedures and a systematic approach across the correctional system to the provision of information and education to inmates about hepatitis C prevention and health promotion.

**Hepatitis C prevention**

The Enquiry endorses the following recommendations and/or proposals for policy or service reform considered in this Report:

40. The NSW Ministerial Advisory Committee on Hepatitis investigate and report on the appropriateness of introducing a needle and syringe exchange program, modelled on the successful European trials, into the State’s correctional system and, if necessary, develop guidelines for the program’s implementation.

41. The Minister for Corrective Services ensure that adequate bleach dispensing machines are available in all correctional centres enabling inmates to access bleach freely and anonymously. Bleach programs should be administered as a hepatitis C control measure and should not be linked to drug surveillance.

42. NSW Health ensure that the CHS has adequate resources to meet the treatment needs of opioid dependent inmates, particularly to ensure access to methadone, and other therapeutic options such as naltrexone and buprenorphine.

43. The Minister for Corrective Services enable tattooing to be available in hygienic conditions within the NSW correctional system. Consideration should be given to:
   - trialing the availability of professional tattooists in the correctional system
   - training inmates in the infection control procedures necessary for safe tattooing and supplying inmates with single use ampoules of ink and autoclaves.

44. The Minister for Corrective Services give consideration to differentiating between the punishment for the use of cannabis and injectable drugs in custodial settings.

45. The NSW Government increase the range of non-custodial and diversionary programs to reduce incarceration.

**Insurance**

The evidence to the Enquiry indicates:

- that people with hepatitis C are being routinely refused insurance or dissuaded from applying for insurance
- that it is common for applications for insurance to be refused without regard to medical evidence about people’s individual prognoses
- such policies and/or practices are inconsistent with current natural history research and clinical evidence about hepatitis C disease progression.

The Enquiry recommends that:

46. HREOC’s proposed public inquiry into insurance discrimination, depression and anxiety disorders be expanded to an inquiry into disability discrimination and insurance to enable hepatitis C related discrimination to be considered.

47. HREOC encourage the participation of key community and industry stakeholders and research bodies including the Investment and Finance Services Association, the Institute of Actuaries of Australia, the Australian Hepatitis Council, the Australian Intravenous League and the National Centre in HIV Epidemiology and Clinical Research.
Funeral Services
The evidence to the Enquiry indicates that:

- family and friends of deceased persons known or assumed to be hepatitis C positive, are routinely denied the right to view the body
- the rationale for refusal on public health grounds, cited by the funeral industry, is inconsistent with the Public Health Act 1991 (NSW) and Public Health Regulations 1991 (NSW).

The Enquiry recommends that:
48. In the context of any proposed changes to the Public Health Act 1991 (NSW) and Public Health Regulations 1991 (NSW), that specific reference to funeral industry practices in relation to the handling of bodies should be retained in the Public Health Regulations.
49. NSW Health, in conjunction with relevant government departments, industry bodies and consumer representation, develop and implement guidelines in relation to the funeral industry, including in relation to the handling of bodies, to ensure compliance with the Public Health Act 1991 (NSW) and Public Health Regulations 1991 (NSW), or such other public health legislation as may be enacted.
50. The WorkCover Authority of NSW, in conjunction with relevant government departments, industry bodies and community representation, develop a Code of Practice on infection control for NSW funeral industry workplaces pursuant to OH&S legislation.
51. The WorkCover Authority of NSW, in conjunction with relevant government departments, work with industry bodies and relevant community agencies to ensure appropriate education and workforce development within the funeral industry to enable effective implementation of the Code of Practice on infection control for NSW funeral industry workplaces.
52. The NSW Government amend the definitions of ‘relative’ and ‘associate’ in the ADA to provide coverage where a person alleges they have been discriminated against on the basis of the disability of a relative or associate who is deceased.

Autopsies
Evidence to the Enquiry indicates that:

- the NSW Institute of Forensic Medicine (Glebe Morgue) has a policy of not reconstructing the bodies of deceased persons with hepatitis C after autopsy and that in cases where viewing of the body is not arranged prior to autopsy, family and friends may be denied the right to view the body
- the policy of the NSW Institute of Forensic Medicine appears to be inconsistent with current autopsy policies and practices elsewhere in NSW and other jurisdictions.

The Enquiry recommends that:
53. Central Sydney Area Health Service determine whether the NSW Institute of Forensic Medicine’s policy has been to refuse to reconstruct bodies where the deceased is known or suspected of being hepatitis C infected.
54. Central Sydney Area Health Service ensure that the Division of Laboratory Medicine, undertaking the work of the Institute of Forensic Medicine, develops and implements a policy on reconstruction of bodies which provides that every effort is made to ensure that the viewing of bodies occurs before an autopsy takes place and, where viewing has not occurred prior to autopsy, that the bodies of deceased persons are reconstructed to enable family and friends to view the body where requested.
55. NSW Health ensure that the proposed statewide statutory authority, the Forensic Medicine and Pathology Authority, once established, develops and implements a policy on reconstruction of bodies which:
   - applies to all agencies within the jurisdiction of the Forensic Medicine and Pathology Authority
   - provides that every effort is made to ensure that the viewing of bodies occurs before an autopsy takes place and, where viewing has not occurred prior to autopsy, that the bodies of deceased persons are reconstructed to enable family and friends to view the body where requested.
56. NSW Health’s Draft Infection Control Policy is amended to provide that every effort is made to ensure that the viewing of bodies occurs before an autopsy takes place and, where viewing has not occurred
prior to autopsy, that the bodies of deceased persons are reconstructed to enable family and friends to view the body where requested.

**Educational settings**

The Enquiry concludes that:

- there is a need for a stronger and more integrated policy response to hepatitis C education in schools
- efforts need to be made to improve policies and procedures in relation to standard infection control procedures and confidentiality in NSW educational institutions
- school-based education needs to address the stigma and discrimination associated with hepatitis C and its relationship to injecting drug use.

**Infection control**

The Enquiry recommends that:

57. NSW Department of Education and Training’s (DET) Prevention of transmission of hepatitis policy is amended to ensure that standard infection control procedures are applied regardless of whether a staff member or student is known to have hepatitis C and the document accurately reflects the differences between the modes of transmission for hepatitis A, B and C.

58. NSW DET support the amended policy with an implementation strategy to ensure that the policy is implemented within educational institutions.

59. Educational institutions report to NSW DET on steps taken to implement the policy within 12 months of the policy’s release.

**Confidentiality**

The Enquiry recommends that:

60. NSW DET develop clear and accessible privacy and confidentiality guidelines which ensure that DET complies with their obligations under the NSW PPIP Act and that appropriate strategies are in place to protect the confidentiality of staff and students with hepatitis C.

61. NSW DET support privacy and confidentiality guidelines with an implementation strategy to ensure that the policy is implemented within educational institutions.

62. Educational institutions report to NSW DET on steps taken to implement the policy within 12 months of the policy’s release.

**Secondary school education**

The Enquiry notes that NSW DET is currently developing curriculum support materials for secondary students related to hepatitis.

63. In formulating the curriculum for secondary students related to hepatitis the Enquiry recommends that:

- consideration is given to the *National framework for education about STIs, HIV/AIDS and blood borne viruses in secondary schools* and the *NSW Survey of High School Students 2000*
- the curriculum enables students to examine the values, attitudes, stereotypes and myths associated with hepatitis C transmission, people who have hepatitis C and those most at risk of infection
- the curriculum addresses discrimination against people who have hepatitis C or are thought to have hepatitis C and discusses anti-discrimination laws
- the curriculum ensures students are taught how to be blood aware and adopt standard infection control guidelines in all situations where blood is present.

**Anti-discrimination legislation**

64. The NSW Government repeal the broad exception for private educational authorities in the ADA.

**Accommodation**

The Enquiry concludes that there is inadequate evidence to determine the extent of discrimination in accommodation against people who use drugs, have used drugs or are assumed to use drugs, particularly given the problems of proof which are commonly associated with allegations of discrimination in the private
rental market. Given that there was insufficient evidence provided to the Enquiry regarding discrimination in the provision of accommodation, no recommendations are made on this issue.

General community — family, friends, communities, media

The Enquiry concludes that people with hepatitis C are often shunned and ridiculed by their own friends, families and communities, leading to increased social isolation and a lack of adequate support. There is also evidence that serious harassment and vilification of people with hepatitis C does occur. There is a need to improve community understanding about hepatitis C. However, significant steps have been taken in recent years to address the level of community understanding about hepatitis C and there are limits to the extent to which knowledge of hepatitis C transmission alone will assist in eliminating discrimination against people with hepatitis C. The Enquiry is of the view that should a social marketing campaign be undertaken, reducing stigmatisation associated with injecting drug use should be a primary aim. However, there was insufficient evidence before the Enquiry to determine whether a social marketing campaign would be effective in addressing hepatitis C related discrimination.

The Enquiry recommends that:

65. The NSW Government amend the ADA to include vilification against people with disabilities, including hepatitis C, which covers conduct that is offensive, insulting, humiliating or intimidating.

Stigmatisation of injecting drug use

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.

Aboriginal and Torres Strait Islander people

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.

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.

**Culturally and linguistically diverse communities**

The Enquiry recommends that:

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.

**Anti-discrimination and other complaint mechanisms**

The Enquiry concludes that:

- anti-discrimination and other complaint-based systems are under-utilised by people with hepatitis C
- people with hepatitis C are often unaware of their rights under anti-discrimination law
- anti-discrimination complaint-based systems place a significant burden on individuals to enforce their rights
- people with hepatitis C face significant barriers in utilising complaint mechanisms provided by anti-discrimination and other legislation
- individual complaint-based systems are inadequate to address systemic discrimination.

The Enquiry recommends that:

73. The Hepatitis C Council and NUAA, in partnership with the ADB, design and implement an anti-discrimination advocacy program to:

- enhance the capacity of the Hepatitis C Council of NSW and NUAA to identify discrimination or unfair treatment actionable under anti-discrimination and other relevant legislation
- support individual access to and use of anti-discrimination and other complaint mechanisms.

74. The NSW Government provide adequate resources to the Hepatitis C Council of NSW and NUAA to develop and implement the above program and provide ongoing individual advocacy services.

75. The NSW Government amend the ADA to enable:

- the President to initiate complaints under the ADA
- the President to intervene in applications for original decisions and Appeal Panel matters.

76. The NSW Government amend section 118 of the ADT Act so that the Appeal Panel can refer a question of law to the Supreme Court, for an opinion of the Court, at the request of the President.

77. The NSW Attorney General’s Department ensure that the ADB is provided with sufficient resources to:

- enable the timely handling of complaints
- take action to address systemic discrimination, such as initiating complaints and intervening in ADT proceedings.

78. The NSW Government enact specific legislation dealing with privacy of health information as recommended by the NSW Ministerial Advisory Committee on Privacy and Health Information.

79. The NSW Government ensure that the NSW Privacy Commissioner is adequately resourced to fulfil this expanded role.
Introduction
1.1 Context

Why conduct an enquiry into hepatitis C related discrimination?

The NSW Parliament’s Standing Committee on Social Issues (the Parliamentary Committee), undertook a landmark inquiry into hepatitis C in NSW during 1997–1998. The Parliamentary Committee’s report, Hepatitis C: The neglected epidemic, was released in November 1998. During the course of the inquiry, the Parliamentary Committee heard considerable evidence about the discrimination and stigmatisation people living with hepatitis C had experienced.

The report states that:

The Committee has come to appreciate that, particularly in relation to the issue of discrimination, hepatitis C is a medical condition, not a political issue or a moral question of right and wrong.

The Parliamentary Committee noted the limited research into hepatitis C (HCV) related discrimination and the absence of government strategies designed to prevent and eliminate such discrimination. A recent review of international and Australian literature related to living with hepatitis C also highlights the lack of research into hepatitis C related discrimination. The reviewers conclude:

There are a number of significant gaps in the literature to date. For example, discrimination and stigmatisation of people living with hepatitis C is mentioned in the context of diagnosis and disclosure and interactions with health care professionals, however, no systematic exploration of this phenomena has been published.

In recognition of the seriousness of the issue of hepatitis C related discrimination, the dearth of research, and the need for improved strategies to prevent and eliminate such discrimination, the Parliamentary Committee recommended that the Anti-Discrimination Board of NSW (ADB) undertake a statewide inquiry into hepatitis C related discrimination to examine the nature and extent of hepatitis C related discrimination, and recommend legal and administrative changes across a wide range of activities. Following representations to the NSW Government by the ADB, funding was provided by the Attorney General’s Department to enable the ADB to undertake this Enquiry.

The purpose of this Enquiry is to ensure we have a more comprehensive understanding of hepatitis C related discrimination. Improved understanding of the extent and nature of discrimination will enable better targeted education strategies, both strategies designed to make people aware of their rights and those designed to prevent hepatitis C related discrimination.

The Parliamentary Committee’s report, Hepatitis C: The neglected epidemic, examines a wide range of issues including: the people at risk of contracting hepatitis C and the extent of infection among particular groups; diagnosis, treatment and management of hepatitis C; the social and economic impact of hepatitis C; and hepatitis C prevention strategies in a variety of key settings such as health care and custodial settings.

This Enquiry does not propose to duplicate the issues adequately and appropriately addressed within the broad ranging terms of reference for that inquiry. This Enquiry aims to respond to the need for an improved understanding of the nature and extent of such discrimination.

Policy and strategic frameworks

Since the Parliamentary Committee released its report there have been significant strategic developments in responding to hepatitis C, at both national and State levels. Of particular importance are the National

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2Hepatitis C: The neglected epidemic, pages 108–119.

3Hepatitis C: The neglected epidemic, at page 119.


5Hepatitis C: The neglected epidemic, Recommendation 21 at page 118. The Committee noted the studies which have documented incidents of discrimination in Burrows, D. and Basset, B. 1996 Meeting the needs of people in Australia living with hepatitis C. National Hepatitis C Council’s Education Reference Group; and Crofts, N., Louie, R. and Loff, B. 1997 The next plague: Stigmatisation and discrimination related to hepatitis C virus infection in Australia, Health and Human Rights Vol. 2, No. 2 at page 89.
Hepatitis C Strategy 1999–2000 to 2003–20041 and the NSW Hepatitis C Strategy 2000–2003.2 Both strategies provide a framework and direction for the prevention, treatment, management and surveillance of hepatitis C, and the care and support of those with the disease. They also acknowledge the importance of reducing the stigma and discrimination associated with hepatitis C.

The National Hepatitis C Strategy identifies four priority areas for action, which are:

- reducing hepatitis C transmission in the community
- treatment of hepatitis C infection
- health maintenance, care and support for people living with hepatitis C
- preventing discrimination, and reducing stigma and isolation.

The National Strategy emphasises that action to prevent discrimination and reduce stigma and isolation is essential if the Strategy’s objectives as a whole are to be achieved. The stigma and discrimination experienced by many people living with hepatitis C, and those at risk of infection, often discourages people from testing. This in turn reduces the extent to which people will access health care services to maximise their health, and receive information and support to reduce the risk of transmission to others. The Strategy recognises that eliminating hepatitis C related discrimination plays a critical role in supporting efforts to reduce hepatitis C transmission and maximise the health of people with hepatitis C.3

While preventing discrimination and thereby protecting people’s human rights has obvious merit in its own right, there is increasing recognition that public health often provides an added and compelling justification for safeguarding human rights...4

The NSW Hepatitis C Strategy also recognises that discrimination has a personal and social impact that needs to be addressed. The NSW Strategy notes that hepatitis C discrimination is covered under the Anti-Discrimination Act 1997 (NSW) (ADA), but acknowledges that the discrimination people experience is not always about people’s hepatitis C status, but rather because of actual, past or assumed injecting drug use.

Discrimination against people who inject drugs, and who are attempting to access services, is an issue that needs to be addressed. They are often discriminated against not because of their HCV status, but because of their drug use, and may therefore be denied care for their illness. All health professionals, including GPs, nurses, accident and emergency staff and medical specialists must be targeted for education.5

The guiding principles and strategies outlined in both the national and NSW hepatitis C strategies indicate a commitment on the part of both federal and NSW governments to address the issue of hepatitis C related discrimination. Such leadership is vital. Nonetheless, given the extent of discrimination demonstrated by the evidence to this Enquiry, significant legislative, administrative and policy changes and education initiatives are needed if a reduction in hepatitis C related discrimination and stigmatisation is to be achieved.

Legislative context — federal and NSW anti-discrimination law

Generally, federal and NSW anti-discrimination laws prohibit discrimination against a person on the basis of their hepatitis C status, in specific areas of public life. Hepatitis C is covered by the disability discrimination provisions of both federal and NSW anti-discrimination legislation.

The ADA and the Disability Discrimination Act 1992 (Cth) (DDA) prohibit discrimination on the ground of disability in areas such as employment, education, accommodation and the provision of goods and services.6 Under both Acts, ‘disability’ is defined to include the presence in the body of organisms causing, or capable of causing, disease or illness.7 This definition encompasses hepatitis C. Both Acts also cover assumed, past and future disabilities, in addition to actually having hepatitis C.8 That is, where someone does not have hepatitis C, but is discriminated against because they are thought to have hepatitis C, have had hepatitis C in

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3National Hepatitis C Strategy at page 2.
5NSW Hepatitis C Strategy, at page 8.
6DDA, Part 2 and ADA, Part 4A.
7DDA, section 4 and ADA, section 4.
8DDA, section 4 and ADA, section 49A.
the past or may have hepatitis C in the future, anti-discrimination laws may apply.

The ADA and the DDA cover direct and indirect discrimination. Generally, direct discrimination occurs where a person with a disability is treated less favourably, in similar circumstances, than a person who does not have a disability. Indirect discrimination on the ground of disability occurs where an unreasonable requirement or condition is imposed that is harder for a person with a disability to comply with, than someone who does not have a disability.

Where a person alleges they have been discriminated against on the basis of their actual, assumed, past or future hepatitis C status, they may be entitled to proceed under either federal or NSW anti-discrimination laws. However, in some circumstances it may be necessary to lodge a complaint under federal rather than NSW laws, or vice versa. For example, where a person alleges they have been discriminated against on the basis of their hepatitis C status in employment and they are a Commonwealth employee, a complaint would need to be made under the DDA and not the ADA.

The NSW Law Reform Commission (LRC) has undertaken an extensive review of the ADA and reported to the Attorney General in 1999. The LRC’s report and responses to that report are being considered by the Attorney General. The ADB has made extensive submissions, both to the LRC’s review of the ADA and to the Attorney General’s Department, in response to the LRC’s report. Recommendations for reform of the ADA outlined in this report have also been raised by the ADB in our input to the reform process.

Despite federal and NSW anti-discrimination laws that prohibit disability discrimination in a wide variety of areas of public life, hepatitis C related complaints under both the DDA and ADA appear to be low. The Enquiry has also found that it is common for people with hepatitis C and those at risk of the virus, particularly people who have injected or do inject drugs, to be discriminated against not on the basis of their actual or assumed hepatitis C status, but rather on the basis of actual, assumed or past drug use. Coverage for assumed, actual or past drug use, under both the DDA and ADA, is currently unclear. This is considered in detail in Chapter 2, section 2.2. The limitations of anti-discrimination laws, both procedural and substantive, are considered in detail in Chapter 4.

While federal and NSW anti-discrimination laws prohibit disability discrimination in a wide variety of areas of public life, not all the evidence provided to the Enquiry falls neatly within the categories of unlawful discrimination provided by federal and NSW anti-discrimination laws. Consideration is given in this report to whether particular incidences of discrimination raised in the Enquiry may be covered by anti-discrimination law and whether amendments are necessary to enable such discrimination to be covered by anti-discrimination law.

For the purposes of this report, a broad interpretation has been given to the concept of discrimination, rather than the narrower interpretation of discrimination as that which constitutes unlawful discrimination for the purposes of anti-discrimination law. Many of the issues raised in the evidence presented to the Enquiry may not necessarily be resolved by resort to anti-discrimination law. However, people’s experiences of living with hepatitis C and the impact of the disease on people’s lives, reveal important insights into the stigmatisation commonly associated with hepatitis C and injecting drug use. This understanding in turn allows a more complete picture of the nature and extent of hepatitis C related discrimination. A broader approach is required to enable consideration of administrative, policy and program responses that may address such discrimination.

1.2 Background

What is hepatitis C and how is it transmitted?

The hepatitis C virus was identified in 1988 and a test to detect antibodies to the virus became available in early 1990. Hepatitis C is a blood-borne virus that affects the liver and is transmitted when the blood of a person with the virus enters another person’s bloodstream.

The main mode of transmission of hepatitis C in Australia is through unsafe drug injecting practices, in particular the sharing and re-using of injecting equipment. Approximately 80% of infections are attributed to the behaviour associated with injecting drug use, another 5–10% to the transfusion of blood products (prior
to 1990) and the remainder to other forms of blood-to-blood contact, such as non-sterile tattooing or other skin-incision procedures. Approximately 91% of new infections are among 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. There is currently no vaccine against hepatitis C.

**Hepatitis C in Australia and NSW**

As the most frequently reported notifiable infection in Australia, hepatitis C is a pressing public health issue. During 2000, 20,926 cases were reported, bringing the total number of notified cases of hepatitis C in Australia to more than 160,000 since the antibody test became available. However, it is likely that many people with hepatitis C remain undiagnosed. It is estimated that 210,000 people in Australia have been exposed to the hepatitis C virus, of whom approximately 90,000 people live in NSW. Of the 11,000 new infections occurring each year, more than 40% of these are thought to occur in NSW.

Up to December 2000, 63,698 people in NSW had been notified as having hepatitis C antibodies. In 2000, there were 8,890 notifications of hepatitis C infections in NSW (see Graph 1), with some Area Health Services showing disproportionately high level of notifications when compared with their respective total populations (see Graphs 2 and 3). Based on current estimates, approximately 40% of people in NSW who have been exposed to hepatitis C are unaware of their status.

**GRAPH 1:** Hepatitis C notifications in NSW 1991 to 2000

*Source: NSW Health AIDS Surveillance Section*

**GRAPH 2:** Hepatitis C notifications (63,698) in NSW 1991 to 2000

*Source: NSW Health AIDS Surveillance Section*

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17 National Hepatitis C Strategy at page 4.
18 Hepatitis C: The neglected epidemic at page 57.
19 Hepatitis C: The neglected epidemic at page 5.
21 Personal communication with Dr Greg Dore, NCHECR, July 2001.
Testing for hepatitis C

The hepatitis C virus (HCV) was discovered in 1988 and a test to detect antibodies to the virus became available in early 1990.

When a person makes a decision to be tested for hepatitis C, a sample of blood is taken and tested to determine whether the person’s body is producing antibodies to the virus (the viral RNA). This is known as an antibody test because it tests for the presence of antibodies, not for the virus itself. After exposure to the virus it can take up to six months before antibodies can be detected. This is known as the window period.

The hepatitis C RNA test, sometimes called PCR (Polymerase Chain Reaction Test), tests for the presence or absence of the virus itself. This test is generally used when assessing people for treatment and can also be used where an antibody test result is indeterminate. There are also a number of other tests used in monitoring people’s health and/or assessing people for treatment, such as tests which determine the quantity of the virus in a person’s system and assess the function of the liver.

Professor Batey, in his evidence to the Enquiry, explains the difference between the antibody test and hepatitis C RNA test as follows:

The virus, once it has infected an individual, leads to some antibodies being produced, no doubt about that. But they’re not particularly helpful antibodies, and in the chronically infected person, the viral RNA remains present in the host, and is now measurable. Testing is still an evolving science and there is no one test that you could do today and be absolutely sure that that would give you the complete information you thought it was going to on your patient… it demonstrates exposure, but not necessarily active infection.

Hep C RNA testing which is done by PCR technology, so those two terms are often used interchangeably to talk about the test for the virus, actually does look for the presence of the virus itself. So a person can be antibody positive, and viral RNA negative, because the virus just isn’t there any more. Equally, early on in an infection, a patient can be RNA positive because the virus is there, and because the host hasn’t yet mounted a proper immune response, the antibody can be negative. So no one test is absolutely able to tell you what is going on if the person, for example, has recently been exposed to positive blood.

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\(^{22}\)NSW Health Department, unpublished data.
\(^{24}\)Professor Robert Batey, Director of the Gastroenterology Unit, John Hunter Hospital Sydney hearing, 15 March 2001. Evidence quoted from the hearings of the Enquiry are taken from tape recordings of proceedings. No written transcript of the oral evidence has been produced.
Evidence provided to the Enquiry indicates there is often a lack of understanding regarding the difference between a positive antibody test and a positive hepatitis C RNA or PCR test. This can lead to discriminatory outcomes, and reference is made elsewhere in this report to specific issues, such as insurance (section 2.6).

The natural history of hepatitis C

The natural history of a disease is defined as its progression in the absence of any medical treatment or other intervention over a designated period of time.\(^2^5\)

Hepatitis C is a slow-acting virus, and for the majority of people infection will not result in serious disease or death. A review of studies into the natural history of hepatitis C has found that approximately 25% of people with hepatitis C infection will clear the virus spontaneously within two to six months of infection (Figure 1); of the remaining 75%, only a small proportion will develop cirrhosis of the liver (Figure 2).\(^2^6\)

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\(^2^6\)Dore, G. 2000 Natural history of hepatitis C virus infection, Hepatitis C: informing Australia’s national response, CDHAC, Canberra.

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**FIGURE 1:** current belief on outcome of acute hepatitis C virus infection

Of 100 people who contract hepatitis C (acute HCV infection)

- 25 clear the virus spontaneously within the first 6 months
- 75 are unable to clear the virus and experience a chronic (ongoing) hepatitis C infection

**Figure 2** indicates the likelihood of illness and severe liver disease among those who have chronic (ongoing) hepatitis C infection.\(^2^7\)

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**FIGURE 2:** current belief on outcome of chronic hepatitis C virus infection

Of 100 people with chronic (long term) HCV infection

- 25 may never become ill
- 75 may eventually develop signs of illness (maybe only mild or moderate)
  - of whom 15 may develop cirrhosis (after 20-40 years)
  - of whom 5 may develop liver failure or liver cancer (after a further 5-10 years)

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1.3 Methodology

The Enquiry has been conducted by the ADB, with hearings chaired by the President of the Board and assisted by members of the Statutory Board. The ADB has been guided in the conduct of the Enquiry by the expertise provided by the Enquiry’s Steering Committee. Members of the Enquiry and Steering Committee are outlined at Appendix A.

Methods for data collection

The ADB has sought the widest possible input from people living with hepatitis C, community-based organisations, relevant government departments, Area Health Services, private sector institutions, and experts in the field. In February 2001, the Enquiry was advertised in *The Sydney Morning Herald, Daily Telegraph, The Australian* and various regional and community newspapers. The ADB produced a poster advertising the Enquiry and factsheets explaining how to participate. The Hepatitis C Council of NSW also produced a factsheet on the Enquiry. These resources were widely distributed by both the ADB and members of the Steering Committee. The ADB’s website has also been regularly updated during the course of the Enquiry. Organisations represented on the Steering Committee have played an active role in distributing information to their clients, communities and professional networks. Media coverage during the course of the Enquiry has also contributed to public awareness of the Enquiry and the issue of hepatitis C discrimination: see Appendix B.

The Enquiry hearings provided both organisations and individuals with the opportunity to speak directly with the Enquiry panel about hepatitis C related discrimination issues. The Enquiry panel conducted a total of 13 hearings including three days of hearings in Sydney, one-day sessions in Lismore, Goulburn, Dubbo, Newcastle and Wollongong, and half-day sessions in a number of correctional centres. Informal private sessions were also conducted at locations such as the Kirketon Road Centre and the offices of the Hepatitis C Council of NSW. Each public hearing included a session open to the public, individuals, workers in the field and media, and a more informal session, closed to the public and media, to enable individuals to tell their stories in a confidential environment. Hearings, both public and private, were tape recorded and notes were also taken during the course of the proceedings.

Discrimination in health care settings is one of the strongest themes to emerge from the evidence. It is important to acknowledge that the methods of data collection may have influenced the extent of the evidence the Enquiry has heard relating to discrimination in health care settings. Health services were an important means of reaching people living with hepatitis C and health care workers who are familiar with the experiences. As a result health services such as community health centres, drug and alcohol clinics, and needle and syringe programs were important sites for the distribution of information about the Enquiry. That health care settings are a key site for discrimination against people who have or are assumed to have hepatitis C is supported by both the submissions to the Enquiry and the limited prior research which exists in this area.

A 1997 study surveyed people with hepatitis C and undertook an analysis of 37 case histories. The study revealed 46% of discriminatory incidents against people living with hepatitis C reported by participants involved health care settings and 20% occurred at work.

The Australian Hepatitis Council’s submission to the Enquiry states:

> It is the experience of community hepatitis C organisations that the most commonly reported instances of discrimination occur within the health services sector.

This view is echoed by many other submissions to the Enquiry. This issue is considered in detail in Chapter 2.

The evidence regarding the experiences of individuals received during the course of the Enquiry is treated as strictly confidential. In order to maintain people’s confidentiality, some submissions have been paraphrased to ensure particular details of stories do not inadvertently breach a person’s confidentiality. Direct quotes are only used in the text where there is insufficient information to enable a person to be identified. Where names appear, these are pseudonyms, designed to enhance the readability of the stories provided. In some instances where evidence has been provided by health care workers on behalf of their clients, particularly in regional areas, quotes and case studies may not include the name of the health care worker or the hearing location.

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28Crofts, N. et al. The next plague: Stigmatisation and discrimination related to hepatitis C virus infection in Australia, at page 89.
29AHC, Submission No. 60.
The Enquiry has received extensive evidence of hepatitis C related discrimination by written and oral submissions. For details about oral and written submissions, see Appendices C and D. An overview of the evidence received and further consideration of the advantages and disadvantages of the Enquiry’s methods of data collection is considered below.

**Written submissions**

The Enquiry received 110 written submissions. Individual’s stories are well represented in written submissions. Well over 50% of written submissions are from individuals writing about their own experiences of discrimination or the experiences of a person close to them.

People with hepatitis C often turn to organisations such as the NSW Users and AIDS Association (NUAA), the Hepatitis C Council of NSW, health services and community legal centres for referral and assistance when they experience discriminatory treatment. The Enquiry has received numerous submissions from such organisations, which are regularly in contact with individuals who have experienced discrimination. In 25 submissions from organisations, multiple individual stories of discrimination are anonymously documented. Table 1 at right provides an overview of the types of organisations that have contributed to the Enquiry, although some organisations may fall within more than one category. A complete list of submissions from organisations, government departments, public and private sector agencies and the like is provided in Appendix D.

**Oral submissions**

The Enquiry panel conducted 13 hearings to take oral evidence and heard from 125 people. Eighty-one (65%) of the participants in the hearings were health and community workers in the field, researchers or representatives of organisations, and 44 (35%) were individuals. However, as with written submissions, many organisations and health workers providing oral evidence presented stories relating to their clients’ experiences of discrimination: see Appendix C for details of Enquiry hearing participants.

The conduct of the Enquiry hearings made abundantly clear the extent to which people living with hepatitis C fear their status being disclosed. The Enquiry was told repeatedly by health workers who are in regular contact with people living with hepatitis C, particularly those working in regional and rural areas, that despite the high levels of discrimination many of their clients experience, many were unwilling to attend even closed hearing sessions for fear that attendance may result in their hepatitis C status becoming known to others in their community or being seen as an injecting drug user.

I’ve talked to quite a few people about coming but unfortunately I don’t think any of them will come because they’re too wary of being seen as [drug] users in the community.\(^3^0\)

Many health workers encouraged their clients to attend, with very limited success.

A client [of mine came] along who was an ex-user, he got to the door of the hearing and found that he felt so uncomfortable that he couldn’t stay.\(^3^1\)

There’s been some pretty horrendous things that have happened to clients and I think they just expect that they won’t be listened to. It’s not so much that they don’t bother, I just don’t think that they think that they’re going to get a fair trial… I think people just want to get what they need to get on with their life. The general community often won’t complain about being mistreated. Community health is a big enough, intimidating enough organisation, and the ADB is big and statewide — it’s like a huge concept for people.\(^3^2\)

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\(^3^0\)Health care worker, Dubbo hearing, 16 May 2001.

\(^3^1\)Health care worker, Dubbo hearing, 16 May 2001.

\(^3^2\)Health care worker, Goulburn hearing, 8 May 2001.
This has undoubtedly impacted upon the number of individual stories contributed to the Enquiry through
the oral hearing process and is a disadvantage with public hearings as a method of evidence gathering.
However, as discussed above, the Enquiry has held closed sessions in every location to maximise people’s
access to the Enquiry hearings. In association with community-based organisations, two closed sessions were
also held specifically for individuals affected by hepatitis C related discrimination. Individual’s experiences are
also well represented in written submissions from individuals and organisations working with individuals
affected by hepatitis C related discrimination. One of the strengths of hearings is that the Enquiry panel has
the opportunity to seek clarification and explore the issues raised by participants. As a result, the quality of
the evidence was enhanced through such interactions.

**Methods of analysis**

The Enquiry proceeded as a qualitative, rather than quantitative, study into the nature and extent of
discrimination against people living with hepatitis C. The evidence gathered has been reviewed and analysed
to identify the range of discrimination issues that have been raised in evidence, the frequency with which
they arose, the groups of people affected by discrimination and the contexts in which discrimination is said
to occur. In the context of the evidence raised during the Enquiry, consideration has been given to whether
anti-discrimination and other relevant laws require reform, whether current public and private sector policies
and procedures are adequate and /or adequately implemented, and what initiatives may be necessary to
eliminate hepatitis C related discrimination and its effects.

The National Centre in HIV Social Research has assisted the ADB in the Enquiry by undertaking a thematic
analysis of the written and oral submissions provided to the Enquiry. For this purpose, written submissions
received by the ADB were released to the NCHSR.\(^{33}\) People were given the opportunity to The aim of this
analysis is to search for themes within the submissions presented to the Enquiry that emerge as significant or
important to individuals. The data for the thematic analysis consisted of notes taken at public hearings and
written submissions from organisations and individuals to the Enquiry. This data were assigned codes and
the information was then condensed into preliminary concepts. Frequency counts of the preliminary
concepts enabled the identification of emerging themes. A theoretical framework concerned with social
identity was applied to complete interpretation of the findings. The NCHSR thematic analysis is produced
in full in Appendix E and references to this analysis are made throughout the report.

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\(^{33}\)Upon 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. Where people did not provide a contact address, submissions were not provided to the NCHSR.
The nature and extent of hepatitis C related discrimination
2.1 Introduction

This chapter focuses on the nature of the discrimination people reported to the Enquiry. The many contributions to the Enquiry, both oral and in writing, have been reviewed and analysed to identify and explore:

- the types of discrimination issues which have been raised in evidence
- the frequency with which the issues arose
- the contexts in which discrimination occurs
- whether particular groups of people or communities were affected by discrimination.

The experiences of discrimination reported have been grouped according to common features, for example, many people have experienced discrimination in the delivery of particular services such as the provision of insurance. Many stories are characterised by the setting in which discrimination commonly arises, for example, in custodial settings and hospitals. In each of these different areas of discrimination, the evidence received is analysed and specific recommendations are made where necessary. Chapter 3 examines the nature of the discrimination that particular population groups or communities of people experience.

A central theme emerging from the evidence is the complex interrelationship between discrimination on the basis of hepatitis C status and discrimination on the basis of drug use or presumed drug use. This is considered in detail prior to considering specific areas of discrimination, as this central theme permeates much of the evidence that follows this discussion.

2.2 The relationship between hepatitis C and drug use discrimination

When an injecting drug user is hepatitis C positive or presumed to be...it is often difficult to know whether it is their status as a drug user or as someone who is or may be positive, that is driving the offending behaviour, or both.¹

The most common mode of transmission of hepatitis C in Australia is through unsafe drug injecting practices. Approximately 80% of people with hepatitis C were infected as a result of injecting drug use. Of all new infections, approximately 91% are among people who have injected drugs. Given the strong correlation between hepatitis C and injecting drug use, and the social stigma associated with injecting drug use, it is not surprising that many submissions to the Enquiry reveal that people with hepatitis C are often discriminated against on the basis of drug use. This is the case regardless of whether the person with hepatitis C has in fact contracted the virus as a result of injecting drug use.

Drug users face discrimination for being drug users, whether or not they’re HCV positive...Users with HCV are doubly burdened. Apart from legal and policy discrimination they face as drug users, they are also likely to wear the mantle of blame and shame that has become associated with HCV. Those who have HCV are likely to face discrimination by people who know very little about the disease simply because they are assumed to be drug users.²

Probably the majority of injecting drug users are living quite functional lives not necessarily engaging in crime and are probably quite an invisible population for [the] most part. It is the very small but significant sub-population of drug users who are engaged in criminal activities, who are very visible to the community, who are street-based, who are involved in sex work and so on, that do tend to feed the stereotypes that the community have and are that part of the population that are of concern.³

I know people that are health care workers, waitresses, people that run housing projects and refuges, plumbers, electricians, people that run small business and TAFE teachers and yoga teachers, I know

¹Ms Annie Madden, Executive Officer, AIVL, Sydney hearings, 2 August 2001.
²Individual Submission No. 46.
³NSW Users and AIDS Association (NUAA), Submission No. 58.
⁴Dr Ingrid van Beek, Director of the Kirketon Road Centre, Sydney hearings, 2 August 2001.
grandmothers and other school teachers, an anthropologist, a truck driver, a drama teacher, a fisherman, farmer and a psychologist who are all ex-injecting drug users.\(^5\)

The social stigma associated with injecting drug use is commonly linked to hepatitis C. It is not uncommon for the media to perpetuate such stereotypes of injecting drug users. This is exemplified by Miranda Devine’s comments in response to newspaper advertisements inviting submissions for this Enquiry:

God forbid that anyone would discriminate against drug addicts...I mean, you wouldn’t want to inhibit their ability to spread a disease which is already contracted by one Australian every hour, with 200,000 victims to date.\(^6\)

Stereotypes aside, such an ignorant comment fails to recognise that discrimination against people who inject drugs actually undermines efforts to prevent transmission of the virus. The impact of discrimination, including the implications for prevention of hepatitis C transmission, is considered in Chapter 3.

In some instances, it is unclear whether the discriminatory or unfair treatment people have experienced is on the basis of drug use or whether it is because the person has hepatitis C. This can make taking action under anti-discrimination legislation more difficult.

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 sure...So, for a variety of reasons, but mostly because it’s difficult to prove what’s being alleged, these cases of judgmental and discriminatory behaviour are not dealt with...So many of the cases that are reported to NUAA, they either don’t fall into the categories outlined in the anti-discrimination law, or they can’t be specifically defined as being a hep C related problem.\(^7\)

The interrelationship between discrimination on the basis of hepatitis C status and discrimination in relation to drug use, whether actual, past or presumed, is evident in the incidents of discrimination provided to this Enquiry. People with hepatitis C are discriminated against on the basis of their hepatitis C status. Examples detailed in this chapter include people being refused health services or placed last on the list for surgery. In addition, as a result of the complex interplay between hepatitis C and injecting drug use, people with hepatitis C are also discriminated against on the basis of actual, past or presumed drug use. Likewise, people who have injected or do inject drugs often experience discrimination on the basis of presumed hepatitis C status as well as on the basis of drug use.

### Drug dependency as a disability under anti-discrimination law

The distinction between discrimination on the basis of present, past or presumed injecting drug use and discrimination on the basis of hepatitis C is of particular significance because of the coverage afforded by anti-discrimination law. As outlined above (see section 1.1), federal and NSW anti-discrimination laws generally prohibit discrimination against a person on the basis of their hepatitis C status in specific areas of public life covered by the legislation. However, it is unclear whether discrimination on the basis of current, past or assumed drug use is covered under anti-discrimination law.

In the NSW LRC’s report *Review of the Anti-Discrimination Act 1977 (NSW)*, the LRC took the view that, as far as is necessary, discrimination on the basis of drug use is covered by the current definition of disability discrimination.\(^8\) However, no NSW or federal anti-discrimination case has decided the issue about whether drug dependency amounts to a disability under either the ADA or DDA. There has been some judicial consideration of whether drug dependence may amount to a disability within the meaning of the DDA, in proceedings before the Human Rights and Equal Opportunity Commission (HREOC) and the Federal Court.

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5 Health care worker, Dubbo hearing, 16 May 2001.
Whether or not drug dependency constitutes a disability within the meaning of the DDA was considered by the Federal Court in Marsden v HREOC & Coffs Harbour & District Ex-Servicemen & Women's Memorial Club. In this case, the complainant, Mr Marsden, alleged he had been discriminated against by the Coffs Harbour and District Ex-Servicemen and Women’s Memorial Club on the basis of his disability, namely his opioid dependence. Mr Marsden had been addicted to heroin in the past and at the time of making his complaint to HREOC was a regular user of prescribed methadone. The complainant appealed against the decision of HREOC. Justice Branson of the Federal Court decided that the tentative view of the HREOC Inquiry Commissioner that drug dependency could not constitute a disability within the meaning of the DDA could not be upheld. In considering the Inquiry Commissioner’s tentative view, Branson J. stated:

In ordinary usage, the words ‘disorder, illness or disease’ encompass a medical condition the symptoms of which can be, and are, alleviated by treatment. Certain disorders are amenable to treatment such that, while taking appropriate treatment, the person suffering from the disorder feels normal and is able to lead a normal life. There are psychiatric conditions, for example, which fit into this category. Nonetheless, in ordinary parlance, the person still suffers the disorder. There is nothing in the DDA which suggests that the words ‘disorder, illness or disease’ in subparagraph (g) of the definition of disability are not intended to bear their usual meaning.

The Federal Court did not make a decision on the question of whether drug dependency can amount to a disability. The original decision by HREOC was set aside and the matter was remitted to HREOC to make another decision. However, when the matter was referred back to HREOC, the case settled. The terms of settlement included that the respondent agreed to releasing a public statement acknowledging that drug dependency amounts to a disability under the DDA. This does not amount to a judicial determination on the issue. In substance, the definition of disability discrimination in the ADA and the DDA are the same. It is therefore arguable that the consideration of the issues is as relevant for complaints lodged under the ADA, as for those lodged under the DDA.

The Federal Court’s decision in the Marsden case received considerable adverse attention in the media. Generally, the media coverage stated that the court had decided that drug dependency amounts to a disability under the DDA. This is not actually the case. Nonetheless, it is worth exploring the concerns raised in response to the proposal that drug dependency may amount to a disability under the DDA. This is so because the concerns raised often reflect a lack of understanding of what such a decision would mean under anti-discrimination law.

For example, the Australian Chamber of Commerce and Industry expressed concern with such an approach on the basis that:

The addiction of employees to drugs or alcohol can have serious effects on the ability of employees to perform in their jobs and to do so safely with respect to their own personal safety and the safety of others on the premises…

While this is undoubtedly true, even if the courts were to decide that drug dependency can amount to a disability under the DDA, such a decision would not affect the fact that under anti-discrimination law an employer is not required to hire a person who is manifestly unfit for or incapable of doing the job required by the employer. Where it is an employer’s view that a person’s drug dependency affects their capacity to undertake a particular job safely, the employer can seek to rely on their obligation to comply with occupational health and safety (OH&S) legislation. The ADA provides that it may not be unlawful to discriminate against a person where such discrimination is necessary to comply with any other Act.

Any applicant with a disability must be assessed against their ability to perform the inherent requirements of a job. If a person with a disability can perform the requirements of the job they should be allowed to compete for it. If the person is the most suitable candidate for the position, anti-discrimination law does require that the employer make arrangements to enable that person to do the job, unless it would cause the employer unjustifiable hardship to do so.

The Newcastle Herald’s interpretation of the implications of drug dependency comes close to exactly what

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5 ADA, section 54.
anti-discrimination coverage would aim to prevent:

Junkies are on the way up. As from this month they are officially disabled people... And so employers, landlords and indeed every commercial organisation will need to revise their limits of tolerance. 'You don't want to employ a heroin addict? Why not? Because he's a heroin addict'.

Making assumptions based upon stereotypes of what a person who is drug dependent can or cannot do is an inefficient and unfair way of determining people's access to employment. So too, a person's actual, assumed, past, present or future drug dependence should not be used as a basis upon which to arbitrarily determine whether a person should have access to particular services or is a suitable tenant. Anti-discrimination law is designed to protect people against irrelevant factors (such as disability, age and sex) being adopted as an unfair and arbitrary surrogate for skill, expertise, fitness and capacity to do a particular job. The mere fact alone that a person is drug dependent, assumed to be so or on a treatment program for their drug dependency should not be a basis on which to arbitrarily determine whether or not a person can perform the inherent requirements of a particular job.

It should also be remembered that not all drug dependency involves illicit substances. A person can be dependent upon a drug which is legally prescribed and provided.

This Enquiry has received considerable evidence which indicates that a person's drug dependency, assumed drug dependency and treatment for drug dependency are often used to arbitrarily refuse people access to services, and as the basis for termination of employment, despite their demonstrated capacity to do their job. These cases are considered in this chapter and Chapter 3.

Whether drug dependency may amount to a disability under the DDA or ADA will depend on the particular circumstances of each case. As a matter of policy, it is the ADB’s view that discrimination on the basis of a person's drug dependency, past dependency, assumed dependency or drug dependency treatment may amount to disability discrimination. Accordingly, the ADB will consider complaints lodged on this basis. Ultimately, this issue is one that requires judicial determination by the Administrative Decisions Tribunal Equal Opportunity Division (ADT). This issue also remains unresolved under the DDA and remains a matter to be determined by the Federal Court.

2.3 Health care settings

Context

The health system in NSW has a highly devolved structure. The Central Office of the Department of Health (NSW Health) sets the broad parameters in matters of policy, planning and finance. Hepatitis C policy is managed by the Health Protection Branch of NSW Health. The AIDS/Infectious Diseases Unit within that Branch has coordinated the health response to hepatitis C, with the Communicable Diseases Surveillance and Control Unit taking a lead role in the area of surveillance.

The provision of hospital and other health services is the responsibility of the State’s 17 Area Health Services and the Corrections Health Service (CHS), working in conjunction with community and non-government agencies and general practitioners (GPs). Area Health Services, the CHS and community-based organisations funded by NSW Health are required to deliver services and programs within the policy and planning parameters set by NSW Health.

General practice is central to the delivery of primary health care and is the major site for hepatitis C testing, diagnosis and management in Australia. Generally, the services of GPs are paid for through the federal Medicare system. As such, they are not accountable to NSW Health with respect to the services they deliver. Although GPs are not part of the NSW Government-funded health services, they are an integral part of the health services essential to meeting the health care needs of people with hepatitis C. The NSW Hepatitis C Strategy 2000–2003 recognises the critical role played by GPs and the importance of effective partnerships between GPs, relevant specialists, nurses and other primary health providers in the delivery of health care services to people with hepatitis C.

NSW Health provides a range of policies, relating to issues such as infection control procedures, which provide the policy framework for all NSW Health funded health services. All NSW Health funded health services are required to comply with these polices and they provide a basis for each Area Health Service to

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14 Addicted and disabled, Newcastle Herald, 29 November 2000.
15 NSW Health, Submission No. 82.
develop detailed policies relevant to their particular settings. Such policies are also recommended for use by professional organisations and private health services in their policy development.

In their submission to the Enquiry, NSW Health acknowledges that instances of discrimination by health professionals against people affected by or thought to be affected by hepatitis C have occurred and continue to occur, both within the public health sector and the private sector. Since the release of the Parliamentary Committee’s report in 1998, NSW Health has taken many positive and significant steps to address the problems which arise for people with hepatitis C, including discrimination.

NSW Health’s submission outlines the key initiatives, drawing particular attention to the development of the *NSW Hepatitis C Strategy 2000–2003*, which was launched by the Minister for Health in October 2000. The Strategy ‘recognises that people with hepatitis C are full and equal members of the community, and discrimination against them is unacceptable and in many instances unlawful’. The issue of discrimination is addressed throughout the document, and some of the initiatives in the Strategy seek to address discrimination in health care settings.

In addition to the development of the Strategy, NSW Health hepatitis C initiatives include:

- providing $3 million over two years to support implementation of the Strategy
- establishing the Ministerial Advisory Committee on Hepatitis
- conducting a mass media hepatitis C public awareness campaign
- funding a NSW Hepatitis C Workforce Development Project
- conducting a review of hepatitis C care, treatment and support services in NSW and developing a plan from it
- providing over $1.7 million recurrent funding to the Hepatitis C Council of NSW and NUAA.

**Overview of the evidence**

Evidence to the Enquiry demonstrates that discrimination within the health care system is prevalent, particularly in hospitals, general practice and dental surgeries. The evidence also raises concerns in relation to the delivery of services provided by pharmacists and alternative therapists. Such discrimination has a negative effect on the relationship between people with hepatitis C and health care professionals, and can become a serious deterrent for people seeking health care.

The Hepatitis C Council of NSW reports that a review of their Hep C Helpline statistics found that health care workers including doctors, dentists, nurses and allied health professionals provoke the most complaints of hepatitis C related discrimination from people with hepatitis C. The HCV Committee of the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) draws attention to the negative consequences of such discrimination:

Discrimination in health care settings, often in the shape of refusal to provide services to people with HCV and/or injecting drug users is of particular concern as it impedes people’s access to essential treatment and care, and prevention and education services. This, in turn, presents a considerable health risk to the wider community.

Discrimination in the context of health care settings takes many forms. The concerns raised do not always fall within the parameters of anti-discrimination legislation, but they are of particular significance because they expose people with hepatitis C to potential or actual unfair treatment. For example, the importance of confidentiality is underscored by the many submissions which indicate that once a person’s status becomes known, whether by voluntary disclosure, inappropriate requirements for disclosure, or as a result of breaches of confidentiality by health care workers, discrimination often follows.

Some key themes emerging from the numerous submissions that raise concerns regarding discriminatory, inappropriate or unfair treatment in health care settings include:

- refusal to provide services
- discriminatory treatment in the course of providing a service
- lack of pre- and post test counselling
- breaches of confidentiality and disclosure issues

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16 Submissions include: South East Sydney AHS, Submission No. 26; Mid North Coast AHS, Submission No. 69; AHC, Submission No. 60.
17 HCC NSW, Submission No. 80.
18 ANCAHRD HCV Committee, Submission No. 47.
Many submissions reflect the interrelationship between hepatitis C and injecting drug use, and many specifically identify that the poor treatment they received was because of discrimination on the basis of drug use or assumed drug use.

People have told us they are often presumed to be an IDU [injecting drug user]...and therefore treated differently. They have told us they are treated as someone who does not have control of their lives, are undeserving of treatment and treated as posing a possible threat to HCWs.20

General practice remains a particularly hostile environment for many people who [have], or who are assumed to have, a history of injecting drug use. Similarly, gastroenterology departments and liver clinics remain opposed to fair and equal treatment for people who inject. This most commonly results in reduced treatment options and inadequate quality of care, particularly in relation to pain relief.22

A number of submissions called on the Enquiry to take care not to alienate general practitioners and other health care providers and emphasised that as such alienation will not improve the quality of health care that people with hepatitis C receive. Professor Michael Kidd, Head of the School of General Practice at Sydney University, stressed that care needed to be exercised to ensure this did not occur.23

The one thing we don’t want to do is turn this Enquiry into a witch-hunt-chasing the medical profession into a corner...The medical profession is just like any other, in that if you do not come into contact with this particular group of people on a regular basis, then you may not be as well informed as you could or possibly should be. There are many sections of the community that could well do with being better informed including medical practitioners, school teachers and employers.24

It is the view of the Enquiry that there is considerable merit in acknowledging the dedication of, and high quality services provided by, many health care workers to people with hepatitis C, many of whom have assisted in the provision of evidence to the Enquiry and recognise the need to address the stigma and discrimination many of their clients have experienced. However, it is also important to acknowledge that discrimination in health care settings is not solely a question of lack of information about or exposure to people with hepatitis C. The evidence points to concerns about the values and attitudes some health care workers bring to their work. It is clear that health care workers are not immune to the same kinds of fears and prejudices held by many in the community.

One of my employees received a needle stick injury and then found that the patient was HCV positive. The doctor was highly distressed and wrote across the front of the file: ‘HCV+'. That is unacceptable, it’s unprofessional and yet very human. I saw that as a frightened response from a colleague of mine...It does bring up in doctors a degree of fear.25

The fact remains that health care workers have a particular obligation to ensure that people with hepatitis C receive the same quality of health care services as other members of the community.

I don’t think the medical profession is more discriminating than other parts of society. I think they reflect the values and attitudes of society generally, but of course they’re in a very important and pivotal role...the onus should be on them to be less judgmental than the community.26


20 Central Sydney AHS, Submission No. 19.

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

22 AHC, Submission No. 60.


26 Dr Ingrid van Beek, Sydney hearing, 2 August 2001.
Testing and diagnosis

The National Hepatitis C Strategy recognises the important role GPs and other primary health care providers play in providing pre and post test counselling including information, support and referral as part of diagnostic testing.27 The importance of access to testing and early diagnosis are also underscored by recent research which concluded that treatment of acute hepatitis C with interferon alfa-2b prevents chronic infection.28

One of the most common issues people with hepatitis C have raised during the Enquiry was testing and diagnosis. Generally, testing is arranged and diagnosis provided by GPs and specialist health clinics.29 The concerns raised in relation to testing and diagnosis relate to the services provided by GPs.

Evidence indicates that people are often advised that they have hepatitis C without any pre- or post test counselling. There is also evidence that blood is taken for a range of tests, including hepatitis C, without obtaining the person’s informed consent to test for hepatitis C.30 For example, the AIDS Council of NSW (ACON) conducted a series of short interviews with 19 people (3 women, 16 gay men) with HIV who are co-infected with hepatitis C to inform their submission to the Enquiry. ACON found that all of the gay men were tested and subsequently diagnosed with hepatitis C as a result of receiving a prior HIV diagnosis. The majority of men stated that unlike the receipt of their HIV diagnosis, they did not receive post test counselling for hepatitis C. The women all received their hepatitis C diagnosis with their HIV diagnosis and while they received HIV post test counselling cannot remember much focus on hepatitis C.31

People have reported being given their test results over the telephone, without information about management of hepatitis C or treatment options.32 A woman reported to the Enquiry that she had been told of her hepatitis C status by her doctor in a manner which suggested she already knew that she had hepatitis C, when in fact she did not.

Dr H opened my file and began, ‘Your hep C is showing up again in this test — is this a recent thing?’ As I went into a state of shock, with my only knowledge of the virus being that it was a chronic liver condition, the phone rang. Dr H stayed on the phone until she was unable to ignore my audible breathing, an effort to calm myself, any longer.33

Evidence also suggests that there is a lack of understanding among some GPs about the distinction between a positive antibody test and a positive hepatitis C RNA or PCR test. For example, one health care worker reports the following implication of a misdiagnosis:

Approximately three years ago I had a patient who was diagnosed as hep C positive after one positive antibody test by her general practitioner.

case study

The main concerns that I have are around GPs...lack of knowledge around transmission, treatment and tests and even what a test result means and how to give the test results to people. I’ve had so many people that have rung me up that have been to their GP who said ‘you’ve got hep C, absolutely’, without any discussion about further testing or any investigations whatsoever, and really scaring the living daylights out of people, basically. And a big emphasis on sexual transmission...people are really scared they’re going to pass it on sexually.

The other thing is not doing pre-test counselling with people. In fact not even telling people that they’re testing them, just sort of chucking hep C in there as just one of the bloods. I’m concerned about the way test results are given. One guy that I knew who came to me very distraught — thought he was going to die within two years — and that he’d infected his whole family. He’d been told over the phone and wasn’t even aware that he’d actually been tested, because he’d presented with other symptoms and the doctor tested him for hep C just while he was there kind of thing.

More recently, just in the last few weeks, there was a GP...who told a young woman very authoritatively that she already knew that she had hepatitis C, when in fact she did not.

Evidence also suggests that there is a lack of understanding among some GPs about the distinction between a positive antibody test and a positive hepatitis C RNA or PCR test. For example, one health care worker reports the following implication of a misdiagnosis:

Approximately three years ago I had a patient who was diagnosed as hep C positive after one positive antibody test by her general practitioner.

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27 National Hepatitis C Strategy at page 33.
29 Health care worker, Goulburn hearing, 8 May 2001.
30 NSW has a network of sexual health clinics throughout the State. These clinics have particular expertise in HIV and other sexually transmitted infections (STIs). Although hepatitis C is not classified as an STI, the expertise of these clinics has meant they are well placed to handle hepatitis C testing.
31 For example: SWOP, Submission No. 53; Southern AHS, Submission No. 43; Health care worker, Goulburn hearing, 8 May 2001.
32 ACON, Submission No. 88.
33 Individual Submission No. 39.
34 Individual Submission No. 103.
practitioner. This result was marked on her medical file. It was later confirmed to be a false positive. Late last year, the patient was brought into casualty requiring sutures to her foot and she was questioned about her positive status. This was extremely distressing to the patient and she thought that no-one believed her. When the patient confronted the general practitioner about having not ordered a HCV RNA PCR test, the GP claimed that in 1998, he did not know the test existed.\footnote{Health care worker, Newcastle hearing, 15 May 2001.}

In evidence to the Enquiry, GPs have emphasised the context in which a diagnosis is often given and the difficulties in getting information across when a person is likely to be distressed or angry as a result of the diagnosis.

We've got ten minutes per consultation. In that ten minutes it's rare that you'd just be focusing on HCV... Post test counselling is something, to do it well, that takes a lot of time...I've had experiences of not being able to meet the needs of some patients who are dealing with a degree of distress related to the diagnosis [of HCV]. Doctors hate that feeling when patients walk out the door and you know there's not been that coming together, a common ground and a moving-on in the healing process. It's not something we ever enjoy.\footnote{Dr Gillian Deakin, Sydney hearing, 3 August 2001.}

People often do not take in a lot in that initial consultation. People may misinterpret what they are told and think the general practitioner is being difficult, especially in the context of the anger which is part of the grief associated with this diagnosis.\footnote{Professor Michael Kidd, Department of General Practice, University of Sydney, Sydney hearing, 3 August 2001.}

The evidence indicates that the quality of information provided in relation to testing and diagnosis has a significant effect upon people with hepatitis C and those at risk of infection.

The way the GP handled my diagnosis had a profound effect on how I saw myself. I felt she judged me...she had very little compassion for me as a person and even less interest in continuing as my GP.\footnote{Individual Submission No. 46.}

Adequate and appropriate information at the point of diagnosis significantly reduces people's fear and gives them a greater capacity to take control of their health.

(I've realised that) HCV is only a diagnosis, it's not a sentence. I thought I had this disease that I was going to die from and I didn't know how long I had or if my life would be debilitated. That realisation gave me back control.\footnote{Individual oral submission, Dubbo hearing, 16 May 2001.}

The Australasian Society for HIV Medicine (ASHM) drew attention to the need to explore practical strategies that will help GPs provide quality information upon diagnosis. ASHM proposes a strategy that is about to be employed in relation to new HIV diagnoses.

When a lab sends a positive result for HIV, an accompanying letter will go with that result to the doctor setting out issues to be included in post test counselling. A booklet will also be sent and a fact sheet for the patient. We could also print information on the bottom of the pathology form which is already being done by some pathology places. There is scope to get information out which will assist in the reduction of discrimination and the identification of appropriate treatment references and support at the point of diagnosis where it's needed most.\footnote{Ms Levinia Crooks, Executive Officer, ASHM, Sydney hearing, 3 August 2001.}

Pre- and post hepatitis C test counselling is vital to the health maintenance of people with hepatitis C and to reduce hepatitis C transmission. As outlined below, the aims of pre- and post test counselling are well documented in the National hepatitis C resource manual.\footnote{National hepatitis C resource manual at page 96.}

The aims of pre-test counselling are to:

- provide information about the processes of being tested
- enable the individual to decide whether or not to be tested
- obtain informed consent, if the decision is to be tested
- provide psycho-social support
- help reduce the risk of further transmission of hepatitis C, through providing relevant information.
The aims of post test counselling are to:

- discuss the meaning of the test result
- provide information about health maintenance and treatment options if the result is positive
- provide psycho-social support for people who test positive
- reinforce transmission prevention messages.

There are some special circumstances where mandatory or compulsory hepatitis C testing may be appropriate, but these situations are rare. For example, testing is a pre-condition for being able to donate blood. Requiring a person to take a hepatitis C test may constitute direct or indirect discrimination on the ground of disability.

Currently, no NSW Health policies provide mandatory guidelines for hepatitis C testing and diagnosis, as they do for HIV. It is now well established that NSW and national policies support HIV testing that is voluntary and follows specific informed consent to testing, with the results remaining confidential. Testing should always be accompanied by appropriate pre-test information and post test counselling.

The need for similar policy statements on hepatitis C was recognised and recommended by the NSW Parliamentary Committee. Currently, ANCAHRD and the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases are in the process of consulting on the draft National Hepatitis C Testing Policy due for release in late 2001. The draft policy reflects the principles outlined above in relation to HIV testing. The policy is currently in draft form and NSW Health has been involved in its development.

There is also a case for the requirement to obtain informed consent, except in specific cases of mandatory and compulsory testing authorised by law, to be enshrined in public health legislation. There are precedents for such legislative requirements. This approach has been supported by the (then) Australian Council on AIDS and Related Diseases and the earlier recommendations of the Intergovernmental Committee on AIDS Legal Working Party in relation to testing for HIV. The rationale for not including the requirement of informed consent within public health legislation has often been that because there is a common law requirement for informed consent there is no need to develop a statutory basis for informed consent.

However, the Enquiry considers that there is a case for enshrining the necessity to obtain informed consent in legislation. Evidence to the Enquiry indicates that the problem associated with informed consent is not that consent to take blood is not sought, but rather that blood, once taken with consent, is tested for hepatitis C without consent. Usually, blood is taken for a whole range of tests. The common law only provides protection where blood is taken without consent, it does not address the issue of blood taken with consent and tested for hepatitis C without consent. Even where the circumstances are covered by the common law, enforcing the requirement to obtain informed consent to testing by resort to the common law is not straightforward and usually requires proof of damage as a result of failure to obtain informed consent.

The Enquiry is of the view that the absence of a legislative statement of a duty to obtain informed consent before testing for hepatitis C needs to be addressed. Given the significance of hepatitis C testing, the requirement for informed consent should be enshrined in legislation and supported by a NSW testing policy.
Hepatitis C testing recommendations

The Enquiry recommends that:

1. The *Public Health Act 1991 (NSW)* is amended to provide that hepatitis C testing of individuals is only carried out with their informed consent, except in specific cases of mandatory and compulsory testing authorised by law.

2. NSW Health, in consultation with the Ministerial Advisory Committee on Hepatitis, develop a comprehensive hepatitis C testing circular, in line with the *National Hepatitis C Testing Policy*, outlining that hepatitis C testing should only occur with informed consent and accompanied by appropriate pre test information and post test counselling.

3. NSW Health disseminate the hepatitis C testing circular to all Area Health Services for implementation in health care services within their jurisdiction.

4. Area Health Services report to NSW Health on steps taken to implement the hepatitis C testing circular within 12 months of the circular’s release.

5. The Ministerial Advisory Committee on Hepatitis and NSW Health disseminate and promote the hepatitis C testing circular to private sector health providers, in particular GPs, through the NSW office of the Royal Australian College of General Practitioners and the Divisions of General Practice in NSW.

6. The Ministerial Advisory Committee on Hepatitis consider mechanisms for ensuring provision of appropriate information to doctors and people with hepatitis C, upon provision by pathology laboratories of a positive hepatitis C test result, in addition to the education strategies outlined elsewhere in this report.

Strategies that aim to support GPs and other primary health providers and improve the quality of information provided to people with hepatitis C at the point of diagnosis are considered below.

Disclosure and confidentiality

Testing, diagnosis, health monitoring and treatment occur in health care settings. People with hepatitis C often need to disclose their status where it is relevant to receiving good health care. A person’s hepatitis C status is more likely to be known or disclosed in health care settings than in any other context. Consequently, by virtue of this fact alone, people with hepatitis C are more likely to experience discrimination on the basis of their hepatitis C status, or because of the association of hepatitis C with drug use. Many submissions to the Enquiry indicate that once a person’s status becomes known, whether by voluntarily disclosure, inappropriate requirements for disclosure, or as a result of breaches of confidentiality by health care workers, discrimination often follows. Confidentiality in health care settings is critical given that information about a person’s hepatitis C status is highly sensitive and there are often adverse consequences when a person’s status is disclosed.

A gentleman went to see a GP and he had difficulty getting an appointment there. He presented and tells me that there was a notation on the front of his file that he saw saying that he was a drug user and that he was HCV+ and that he was ‘not to be seen’ so that if the receptionist picked that up she would know not to make an appointment for him…not welcome basically.\(^{48}\)

The Enquiry has heard numerous examples of breaches of confidentiality within health care settings and by health care workers to third parties such as prospective employers and family members. Breaches of confidentiality in health care settings occur in a variety of ways. Evidence to the Enquiry indicates that inappropriate signs, other forms of labelling such as coloured wrist bands identifying patients with hepatitis C, and poor practices and/or procedures for ensuring confidentiality of health records commonly leads to disclosure of people’s hepatitis C status in health care settings.

On the top of the hospital chart on the end of the bed was written ‘Hepatitis C+’ in red texta…what that had to do with the cleaning staff and the people who were delivering food and anybody else who happened to walk in there, I have no idea…\(^{49}\)

\(^{48}\) Health care worker, Dubbo hearing, 16 May 2001.

The Enquiry notes that many submissions raise breaches of confidentiality in maternity wards. This often had profound effects upon the women concerned, both emotionally and in terms of the quality of care provided.

I was having complications with the pregnancy of my first child 6 years ago. When the nurses/midwives discovered I was hep C positive they put me in a private room and told me to handle all of my bedding/towels etc. They made me feel like a dirty diseased person. This reaction has affected me emotionally a great deal in the following years.51

When ‘Sarah’ went to the nursery to visit her newborn child, she was horrified to see the baby’s crib had a large red sticker on it stating the child and mother were HEP C+. When Sarah complained about the sign she was told by a senior staff member ‘It doesn’t matter, you are a drug user, so everyone knows you are hep C positive anyway.’ After two days, Sarah signed herself out of hospital and she states that she experienced many difficulties as a result of her premature departure from hospital.52

The Alcohol and Other Drugs team was asked to see a woman on the maternity ward who was receiving methadone. We could not find her file in the usual slot — it was at the front desk to the Unit, in an open rack visible to the public, where both her name and a large red sticker proclaiming ‘Hazard — Hepatitis C Positive’ were clearly visible.53

Evidence to the Enquiry indicates that people are often asked to complete forms which specifically ask people to indicate whether they have hepatitis C before they can access a particular service. Such practices appears to be particularly common when people present for dental work or surgery and are often based upon the misapprehension that knowledge of a person’s status is the best way to prevent hepatitis C transmission. This is a flawed approach to infection control and is considered in more detail below.

I waited three months to see the dentist. The day came, I had to fill out a form, and it came to hepatitis C. I didn’t know whether to tick it or not because I knew that people wouldn’t like dealing with it…the dentist made the excuses about why he couldn’t do the job…it’s made me really wary whether to tell the truth and tell people I have Hep C. I feel like I should, so in actual fact I’ve stopped going to dentists and doctors.54

I applied for a job in a child care centre; the application required a medical certificate. I went to my local GP and much to my surprise the doctor insisted that she would have to disclose my hepatitis C. I asked why as I am perfectly fit. I was told that I might pass it on. (My GP would not have known I had hepatitis C if I had not previously informed her.) I said if she was going to disclose, there was little point in me proceeding with the application and burst into tears. When I left the surgery I tore up my application.55

Generally, people with hepatitis C are not required to disclose their status, although they may do so in health care settings because it may be relevant to the service they are seeking. As outlined above, in the majority of circumstances hepatitis C testing is voluntary. Compulsory testing is only legal in rare situations. There are some very limited circumstances in which testing or knowledge of one’s HCV status is required. For example, testing is a pre-condition for being able to donate blood. Requiring a person to take an HCV test may constitute direct or indirect discrimination on the ground of disability.

Evidence provided to the Enquiry, particularly during the course of the Enquiry’s regional hearings, emphasised that breaches of confidentiality can have particularly damaging consequences in smaller communities.

A woman living in a small country town, in her words — ‘where everyone knows everyone’, travelled approximately 50 km to the next town to see a GP, as she didn’t feel that her confidentiality would be

50 Hepatitis C Helpline (Victoria), Submission No. 54.
51 Professor Sandy Gifford, Public Health, Deakin University, Survey of women living with hepatitis C in Victoria and ACT, Submission No. 94 — Experience of discrimination among women living with hepatitis C.
52 Individual Submission No. 95.
53 Rod McQueen, Staff Specialist Population Health Unit, South Western Sydney AHS, Submission No. 97.
54 Health care worker, Submission No. 90.
55 Individual Submission No. 9.
respected … She told me that she basically did not want to lose her standing within the community or have her family treated as outcasts.56

Particular concerns regarding confidentiality were also raised in relation to people from culturally and linguistically diverse communities. People fear their status being known within their communities and are often too scared to disclose their hepatitis C status to health care workers. As a result they often fail to access the necessary health care services to enable them to monitor their health and access treatment.57

The North Sydney Area Health Service’s HepCare study found that non-disclosure was commonly utilised by many people with hepatitis C as a means of preventing discrimination associated with their hepatitis C. Such non-disclosure often has ramifications in terms of people with hepatitis C accessing the range of health and social services required to effectively manage their health needs.58

Legislation and policy in relation to confidentiality and privacy

Breaches of confidentiality are unlikely to amount to discrimination under anti-discrimination legislation. Nonetheless, disclosure of a person’s hepatitis C status often leads to discriminatory treatment.

Currently there is no single, comprehensive piece of privacy legislation in NSW that applies to the private and public sectors. Rather the legal framework applying to health information is a patchwork of different laws and includes:

- privacy legislation in NSW applying to public sector agencies — the Privacy and Personal Information Protection Act 1998 (NSW) (the PPIP Act)
- some health-related legislation, with specific provisions on confidentiality, in some cases for specific conditions which do not include hepatitis C, such as section 17 of the Public Health Act 1991 (NSW)
- federal privacy legislation — the Privacy Act 1998 (Cth), as amended by the Privacy Amendment (Private Sector) Act 2000 to extend coverage to the private sector in Australia59
- common law medical confidentiality obligations applying to the practitioner–patient relationship
- various laws requiring the mandatory reporting of information by practitioners, including public health and child protection legislation.

NSW Health has prepared a comprehensive Privacy Management Plan in accordance with the requirements of the PPIP Act. NSW Health has also developed an Information Privacy Code of Practice (distinct from the type of Code issued under the PPIP Act), and this will remain a central policy document for the way in which NSW Health handles personal information.60 The adequacy of privacy legislation is considered in more detail in Chapter 4.

The NSW Health Minister established the NSW Ministerial Advisory Committee on Privacy and Health Information (‘the Committee’) in June 2000. The Committee was appointed to investigate and advise on privacy issues relating to health information, particularly those raised by the proposed electronic health records. The Committee reported to the Minister for Health in December 2000.61 The Committee made a range of recommendations, the most important of which is that the system of linked electronic health records be governed by a separate and specific piece of State legislation.62

One of the major limitations of the PPIP Act is that it only provides legal remedies in relation to privacy breaches by public sector agencies. If the Committee’s proposal for legislative reform is acted upon, such legislation would cover health information regardless of who possessed it. Significantly, this would cover health information held by private sector health providers and employers. The NSW Government has indicated its support for the Committee’s recommendations. Recommendations regarding legislative reform are considered in Chapter 4.

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57 HCC NSW, Submission No. 80 and Multicultural HIV/AIDS Service, Submission No. 64.
58 North Sydney AHS, Submission No. 71.
61 Panacea or Placebo? Linked Electronic Health Records and Improvements in Health Outcomes, NSW Ministerial Advisory Committee on Privacy and Health Information - Report to the NSW Minister for Health, December 2000, Sydney.
62 Panacea or Placebo? Linked Electronic Health Records and Improvements in Health Outcomes, recommendations 3 - 5 at pages 4 - 5.
The Public Health Act 1991 contains a specific confidentiality provision in relation to non-disclosure of a person’s HIV status. The provision covers medical practitioners and any person who in the course of providing a service, acquires information that the person has, or is required to be or is to be tested for HIV or has HIV or AIDS. A NSW Health circular specifically outlining the legal requirements in relation to HIV/AIDS and confidentiality supports compliance with both statutory and common-law obligations in relation to confidentiality.

The Enquiry recognises that both the Public Health Act and Regulations are currently under review. At the time of writing, input to a review of the Public Health Act and Regulations has been considered by NSW Health and recommendations have now been made to the NSW Government about proposed amendments. The Government’s views regarding proposed reform of the Public Health Act and Regulations are not publicly available.

Confidentiality and privacy recommendations

The Enquiry recommends that:

7. Section 17 of the Public Health Act 1991 (NSW) is amended to include hepatitis C and thereby provide a specific confidentiality provision in relation to non-disclosure of a person’s hepatitis C status in the same terms as the Public Health Act currently provides in relation to HIV.

8. NSW Health, in consultation with the Ministerial Advisory Committee on Hepatitis, develop a circular which provides clear guidelines on legal requirements in relation to hepatitis C and confidentiality.

9. NSW Health disseminate the circular on hepatitis C and confidentiality to all Area Health Services for implementation in health care services within their jurisdiction.

10. The Ministerial Advisory Committee on Hepatitis and NSW Health disseminate and promote the circular on hepatitis C and confidentiality to private sector health providers, in particular GPs.

11. NSW Health revise its Privacy Code of Practice 1998 to include hepatitis C within the list of ‘special information categories’.

12. Area Health Services take all necessary steps to promote compliance with privacy legislation and the Privacy Code of Practice 1998 within their health care facilities.

13. Area Health Services provide a report to NSW Health, within 12 months of the circular’s release, on steps taken to:

   ■ promote compliance with privacy legislation and the Privacy Code of Practice 1998
   ■ ensure implementation of the circular on hepatitis C and confidentiality.

The adequacy of privacy legislation is considered in Chapter 4, including recommendations for legislative reform.

Refusal of services or less favourable treatment in providing services

Evidence to the Enquiry indicates that it is common for people with hepatitis C to be refused health services, particularly dental work and surgery, when they are known or assumed to have hepatitis C.

It was only yesterday we were talking to a young fellow. He had had the same doctor since he was seven years old. He had some testing done and it came back HCV+ and his GP said to him ‘now that we know that, that’ll be it — no more consultations. I don’t want to see you again’.

[I] had to have an LFTs [liver function test] done at the local hospital…[I went] to get blood taken…The nurse asked ‘is this an LFT do you have hep C’. I said that, ‘yes, I have hep C’ — the nurse then refused to take the blood. Another nurse came over, apologised and took the blood.
A client presented to Accident and Emergency with severe liver and stomach pain, they’d been drug free for a couple of years, they were accused of drug-seeking behaviour [when seeking pain relief] and informed ‘We have sick people to deal with here’.

I was in hospital for five and a half weeks bed-ridden, I couldn’t move…from the time they found out I had HCV, I had absolutely no assistance whatsoever to shave, to bathe, nobody ever came and helped me change my position…I came out of hospital at 39 years old, with bedsores.

The Enquiry heard evidence from many people with hepatitis C who felt that the quality of their care was significantly diminished or they were treated less favourably once their hepatitis C status became known.

A registered nurse noted that the patient’s intravenous cannula had been in situ for four days. The policy states that these must be replaced every two days due to increased risk of infection if left for longer. When the nurse pointed out that the cannula was overdue for change, the nurse from the previous shift stated that because the patient had HCV, the cannula had been left in because changing it represented an occupational health and safety risk for staff.

[I] went to a dentist because I had an inflamed gum. The dentist started to lecture me about drug abuse after I told him I was hep C positive. He said how can I help you when you have an abusive lifestyle. I told him that I had not used drugs for 13 years and I [was] reduced to tears.

When you disclose to them your status, you see a shift and they treat you differently, but what can you do about that? How do you make a complaint about someone’s attitude, and who would believe you anyway? 71

I went into a small country hospital and they put me in a room by myself. I told them I wasn’t a private patient. They said I was there because I had hep C. I hadn’t told the nursing staff…the doctor must have told them before my admission. The people who delivered the food wouldn’t come into the room.

A recent study involving over 600 women with hepatitis C found that almost one half (48%) of the women said they had received less favourable treatment from health professionals because of their hepatitis C. Of the women who became pregnant (n=174) after being diagnosed with hepatitis C, 9% were advised to have a termination because of their hepatitis C.73 A number of other submissions indicated particular concerns regarding discriminatory treatment flowing from disclosure in the context of antenatal and post natal care: see above in relation to disclosure and confidentiality.

Pain management

Many people with hepatitis C have raised concerns regarding inadequate pain management or refusal to provide any pain relief in medical settings. The evidence indicates that this occurs regardless of whether the person actually has a history of drug use. When people have a history of drug use or are currently using drugs, health care workers often make assumptions that people are ‘drug seeking’, rather than considering whether pain relief is appropriate and if so, what dosage is appropriate in the circumstances.

The Enquiry has also heard considerable evidence from GPs about the difficulties in determining when it is appropriate to provide pain relief and the stringent requirements with which the medical profession need to comply.

We have very stringent restrictions on us as to what we can prescribe and how. We have to be very careful with the dosages that we use. We know that there are people who have used narcotics that require higher doses for pain management than someone who hasn’t had

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69 Mid North Coast AHS, Submission No. 69.
70 North Sydney AHS, Submission No. 71.
71 NUAA, Submission No. 68.
72 Individual Submission No. 51.
73 Professor Sandy Gifford, Submission No. 94.
74 Individual Submission No. 92.
that experience. But you have to have a therapeutic relationship with this patient to know what you can
prescribe, what you can say and do…it puts our registration at risk to become identified by the Health Care
Complaints Commission as being a doctor who is inappropriately prescribing. It almost becomes a battle
between the doctor and the patient.75

If someone walks in off the street and says “I’ve got this terrible pain in my back, can I have something
strong for it?” and we’ve never met them before, particularly if they present as a drug and alcohol patient, it’s
very problematic (to provide pain relief). If it’s someone who regular attends the practice, we know them very
well and [if] they present in pain it can be dealt with in a much easier way…I have had very disruptive and
quite frightening visitations from the Pharmaceutical Services Branch assuming that I was a rampant
prescriber of narcotics…my judgement was validated and the patient did need large amounts of
narcotics…[but] I had to prove my innocence, I was guilty until proven innocent. It took me hours, I had to
produce evidence of the patient’s history… it was all done in a very hostile way.76

There are complexities in determining whether pain relief is appropriate in a particular set of circumstances.
Nonetheless, the evidence to the Enquiry suggests that pain relief is often denied to people with hepatitis C.
This appears to be so even where the health care worker does not know whether the person has a history of
injecting drug use. The evidence indicates that pain relief is often refused without a considered assessment of
whether a person’s current or past drug use may be relevant to the provision of pain relief in the
circumstances.

Inappropriate infection control strategies

People with hepatitis C are not required to disclose their status for infection control purposes. NSW Health
has developed a comprehensive infection control policy, which provides clear guidance on the standard
infection control procedures necessary to prevent the spread of blood-borne viruses such as hepatitis C in
health care settings.77 Infection control is also incorporated into legislation and/or regulations for medical
practitioners, nurses, physiotherapists, dentists, dental technicians and podiatrists in NSW. Under the
relevant Acts, practitioners must not, without reasonable excuse, fail to comply with infection control
regulations. For example, the Dentist (General) Regulation 1996 (NSW), has recently been amended and now
sets out standard infection control procedures which must be applied by all dentists.78

Standard infection control procedures are designed to be routinely applied, regardless of whether a person is
known or assumed to have hepatitis C. Infection control procedures are commonly called ‘universal’ or
‘standard’ procedures, precisely because they must be consistently applied. Given that approximately 40% of
people in NSW who have been exposed to hepatitis C are unaware of their status, infection control measures
based on assumptions or knowledge about a person’s hepatitis C status would be ineffective in reducing the
risk of transmission. The application of standard infection control procedures is essential in reducing the risks
of hepatitis C transmission within the health care setting. Such procedures, consistently applied, also ensure
that people with hepatitis C are not required to disclose their status and that where a person’s status is
known, there is no need for their status to be disclosed to other health care workers in the misguided view
that this is necessary for infection control purposes. Infection control practices that rely on knowledge of a
person’s hepatitis C status expose both health care workers and patients to the risk of infection. This in turn
exposes Area Health Services in terms of their legal obligation in relation to the health and safety of their
employees, and their duty of care to their patients.

Despite a clear NSW Health infection control policy, one of the most common problems people with
hepatitis C experience is disclosure of their status in the name of infection control. This is often the result of
ill-informed fears regarding hepatitis C transmission, and inadequate knowledge and/or inappropriate
application of standard infection control procedures. Evidence to the Enquiry indicates that poor knowledge
and application of standard infection control procedures commonly occurs in hospitals and dental surgeries.
This exposes people to the potential for discrimination and often leads to actual discriminatory treatment.

75 Professor Michael Kidd, Sydney hearing, 3 August 2001.
76 Dr Gillian Deakin, Sydney hearing, 3 August 2001.
77 Infection Control Policy, NSW Health, Circular 99/87. This policy is currently being updated and a revised draft policy is currently under
consideration.
78 The Dentist (General) Regulation 1996 (NSW), was amended by the Dentists (General) Amendment (Infection Control Standards)
Regulation 2000 (NSW), and commenced on 17 November 2000. Clause 21 of the Dentist (General) Regulation 1996 (NSW) provides that a
person engaged in the practice of dentistry must not, without reasonable excuse, fail to comply with the infection control standards set
out in Schedule 2 to the extent that they apply to the person in the practice of dentistry.
While in hospital I had to wear a different colour armband which distinguished me from other patients. My baby also stood out from the others with ‘universal precautions’ written all over her cot. I thought hospitals had standard precautions in place for all patients, so I’m not sure why we had to stand out from the others.79

A person was referred by a treating dentist to a specialist to have a number of teeth extracted. The dentist told him that he must disclose to them that he has HCV when making my appointment so that they can schedule me as the last appointment for the day. “I asked why…and was told that they would literally hose down everything in the room afterwards…‘in your case we want to wipe down every inch of the room.’”80

A survey of the knowledge and attitudes of 1,577 registered nurses across Australia was conducted in 1998. The findings show a clear lack of knowledge among many respondents which often manifests in the adoption of inappropriate infection control strategies.81

Some of the findings include:

- 25% of nurses agreed with, or were unsure, about the statement, ‘patients with hepatitis C should be nursed in an isolation ward’
- 40% agreed that they should be free to choose whether they directly care for a patient with hepatitis C and another 19% were unsure whether this should be so82
- 25% of respondents acknowledged that they felt uncomfortable working with colleagues who have hepatitis C
- 18% agreed or were uncertain about whether patients with hepatitis C should be specifically identified using coloured armbands, even though this is not NSW Health policy or practice.

Last in the surgery queue

Evidence to the Enquiry indicates that when a person is known or assumed to have hepatitis C, they are often placed at the end of the surgery list. This means infection control procedures are being applied to reduce the risk of transmission only where a person is known or assumed to have hepatitis C. Practices such as placing people with hepatitis C last on the list for surgery create an environment where reliance is placed on having knowledge of people’s hepatitis C status and unnecessary disclosure is required. As outlined, infection control measures based on assumptions or knowledge about a person’s hepatitis C status are ineffective in reducing the risk of transmission, when a significant proportion of people are unaware of their hepatitis C status.

On the day of the operation I arrived at 1:00 pm. I went to the surgical ward and I was told by a nurse to wait in the waiting room. Shortly after this I heard someone from the nurses’ desk say ‘______ is here, he is the last cab off the rank’. Then the head of the ward came in and abruptly stated ‘make yourself comfortable, you have a very long wait ahead of you, the list has been changed, you are last and we do not have a bed for you.’83

I will invariably be the last patient through the hospital procedure room, it doesn’t matter if they’ve asked me to sit there since 7.30 in the morning…you can bet your bottom dollar that I will be there at 3.30 in the afternoon…I don’t mind waiting but I think that they could be a little bit more realistic and go ‘Look, why don’t you come in at 12.30pm, you don’t need to fast for breakfast just don’t have lunch’…you do feel marginalised, you do feel discriminated against, you do feel less than, so I don’t see that it would cost (hospital staff) anything to ameliorate that feeling for the patient by treating them as you would treat any educated, thinking person and tell them what’s going on…”84

A client had to go and have skin surgery…when she went to see the surgeon she thought she’d be honest and say ‘Yes I have had HCV’…from that moment on she was told that she would be on the ‘dirty list’, she was told that the sheets that they used on the surgery would be burnt, that she would be the last one on the day.85

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79 TRAIDS, Submission No. 61.
80 Individual Submission No. 65.
82 Despite this view, it is clear that health care workers are not entitled to refuse to provide services on the basis of a person’s hepatitis C status: see coverage under federal and NSW anti-discrimination law below.
83 Individual Submission No. 91.
The Australian Dental Association (NSW Branch), in their submission to the Enquiry, indicate that they strongly support and encourage their members, through regular education programs and provision of resources, to adopt universal infection control measures. A study of blood-borne virus-related discrimination in dental services was undertaken in 1998. Key stakeholders including dentists, hepatitis C and HIV/AIDS organisations, and State and Territory health authorities, were invited to review policies, procedures, organisational arrangements and other systemic issues which influence the quality of oral health services. The consultations highlighted that:

- continuing education concerning infection control procedures is fundamental to reducing discrimination in health services
- monitoring infection control procedures was critical, with many consulted agreeing that such monitoring should be linked to accreditation of dental workplaces.

Given the recent introduction of infection control procedures into the Dental (General) Regulations 1996 (NSW), as outlined above, there is an opportunity to improve knowledge of infection control procedures among dentists and to support compliance with the regulations.

Non-discriminatory policies and practices, particularly standard infection control procedures, are more likely to influence the culture of institutions and professional groups where:

- the rationale for such procedures is well understood
- implementation occurs in the context of existing quality assurance systems.

The Enquiry concludes that:

- there is a poor understanding among health professionals of the rationale for standard infection control procedures
- there is an urgent need to improve the implementation of standard infection control procedures particularly in hospitals and dental surgeries
- effective implementation of standard infection control policies and procedures are essential to reduce discrimination in health services and ensure the safety of both patients and health care workers.

Infection control recommendations

The Enquiry recommends that:

14. Area Health Services ensure that:

- hepatitis C education for health care workers includes standard infection control procedures, and assesses health care workers’ knowledge of such procedures and their understanding of the rationale for standard infection control procedures
- all health services within their jurisdiction have in place standard infection control procedures appropriate to their health setting and that the implementation of standard infection control procedures occurs in the context of existing quality assurance systems at service level.

15. The Australian Dental Association (NSW Branch):

- undertake ongoing education concerning standard infection control procedures that incorporates the rationale for such procedures
- ensure that implementation of standard infection control procedures is adequately monitored
- link adequate systems for monitoring standard infection control procedures to accreditation of dental workplaces.

Access to hepatitis C treatments

The standard therapy now used in the treatment of hepatitis C is interferon used in combination with ribavirin (combination therapy). The aims of treatment are to stop viral replication and eliminate the virus, and to subsequently prevent the development of cirrhosis, liver failure and liver cancer. Treatment is recommended for people who have a chance of clearing the virus and for people most at risk of developing...
cirrhosis. People with cirrhosis have a lower response rate to treatment, but it is thought that treatment will slow down the progression of liver disease.88

Combination therapy offers sustained improvement in liver functions, viral suppression and possible viral clearance in up to 65% of people with a favourable genotype and low viral load.89 Subsidised treatment is made available to people who meet certain conditions under the Highly Specialised Drugs Program (section 100 drugs) of the Pharmaceutical Benefits Scheme (PBS).44 The criteria for access to subsidised hepatitis C treatment has been broadened, effective as of 1 May 2001, to reflect improved knowledge gained through clinical research, resulting in increased numbers of people being eligible for subsidised treatment.

Prior to changes introduced in 1998, the section 100 criteria denied access to subsidised treatment for current injecting drug users and people with HIV co-infection. Despite changes to the criteria, evidence to the Enquiry indicates people with hepatitis C who inject drugs continue to be denied access to combination therapy.

Whilst [the section 100] guidelines have been changed…the practice by GPs around those guidelines hasn’t necessarily changed. There are some specialists and GPs who still believe it’s not appropriate to give drug users access to treatments until they stop using.91

Frequently, when hepatology specialists are asked whether they would treat a current injecting drug user, the answer is no. Hepatitis C Council staff have heard such responses from specialists in conferences, forums and education sessions. This occurs largely because many health care providers believe that a client’s drug using should be addressed before hepatitis C can be treated. This is partially due to fears of re-infection. This assumes that all drug use is problematic and that injecting drug users’ lives are chaotic, regardless of lack of evidence of instability.92

Recent research in The Netherlands also indicates that such beliefs regarding injecting drug use may run contrary to reality. A recent trial of combination therapy for people with hepatitis C and who also inject illicit drugs had a compliance rate of 90%, compared with compliance rates of 70–80% in treatments for other conditions where trial participants were not injecting drug users.94

Concerns regarding the risk of reinfection appear to contribute to the practice of denying people who currently inject drugs access to combination therapy. Evidence to the Enquiry reinforced the current section 100 guidelines, that the risk of reinfection alone should not be the basis for refusing currently injecting drug users access to combination therapy.

HCV appears not to have any immunity attached to it. Either viral clearance by the body itself or viral clearance through anti-viral treatment. Either of those mechanisms can eradicate the virus but people who eradicate the virus are as prone to re-infection as other people. That’s one of the points I discuss with people living with HCV who are currently injecting. I certainly don’t use that as exclusionary criteria but I discuss with them the possibility of re-infection.95

When people are refused access to treatment on the basis of their drug use, coverage under anti-discrimination legislation remains unclear. This issue is considered in detail in section 2.2.

Evidence to the Enquiry has also raised broader concerns regarding the difficulties people who inject drugs face in accessing health services generally, which obviously impacts upon their access to hepatitis C treatment specifically.

As the people most affected by HCV, people who inject drugs have by and large stayed away from HCV treatments in droves...[people who inject drugs] don’t want to have to deal with the attitudes, the moralism, the lack of pain management if it’s needed, the constant disbelieving, having symptoms minimised or dismissed and having to deal with the fact that GPs and specialists are far more concerned about your drug use than your HCV treatment and management needs. You don’t get treated as a whole person as a drug user, you get treated as someone with drug use issues.
We need to provide access to HCV treatment and management services in environments where IDUs (injecting drug users) are comfortable. A lot of drug users won’t go to general practice because they’ve had really bad experiences. There seems to be quite a lot of money going into programs focused around enhanced primary care which is not a problem…but we do believe that there could be more effort put into providing sessional clinics in drug user organisations and HCV councils and places where drug users are already accessing services.96

Evidence to the Enquiry, particularly during the course of regional hearings, indicates that people with hepatitis C living in regional and rural areas experience particular difficulties in accessing treatment. This is the result of a number of factors, the most significant of which is that people living in regional and rural areas have significantly less access to GPs, particularly those with expertise in the monitoring and management of hepatitis C. This has obvious implications for people’s access to hepatitis C treatments in particular. While it is possible, indeed desirable, for GPs to undertake the initial work up to determine whether a person with hepatitis C should consider treatment, access to GPs with sufficient knowledge to do so is more limited in regional areas. People with hepatitis C often have to travel long distances, on numerous occasions, for initial and subsequent assessments in order to access treatment.

There’s been some analysis done in other States, for example in Queensland it takes 13 visits to the liver clinic in order to go on treatment. Many of those activities could have been done in general practice. For someone who’s got to travel a great distance then there could have been an appropriate service delivered to them locally. We need to look at mechanisms for normalising the treatment of HCV. Treating HCV is not particularly difficult or sophisticated. It’s not as if we’re looking at a large cluster of drugs that need to be used.97

There are a number of educational strategies and models of care being developed and trialed which are designed to support general practice and enhance the capacity of GPs to improve access to hepatitis C treatment for people in regional and rural areas. These initiatives are considered in section 3.7.

The evidence indicates that people who live in regional and rural areas face difficulties undertaking combination therapy in relation to accessing the medication and adequate psychosocial support during the course of their treatment. In particular, there are difficulties associated with the long distances people with hepatitis C need to travel in order to have their prescriptions filled through hospital pharmacies.98 There are also particular complexities in relation to the requirements for delivery of section 100 drugs under the Pharmaceutical Benefits Scheme.

The issue of access to hepatitis C treatment is currently being considered by the NSW Ministerial Advisory Committee on Hepatitis, including options to broaden access to prescribing rights to some GPs and private gastroenterologists.

The difficulties people living in regional and rural areas face in their access to health services are not unique to people living with hepatitis C. Clearly, these difficulties impact upon the health of people living with hepatitis C, but are not the consequence of discriminatory treatment on the basis of their hepatitis C status.

**Access to treatment recommendations**

The Enquiry recommends that:

16. The NSW Ministerial Advisory Committee on Hepatitis consider and determine appropriate strategies to improve access to best practice therapy for people who currently inject drugs.99

17. The NSW Ministerial Advisory Committee on Hepatitis consider and determine appropriate strategies to improve access to best practice therapy for people living in regional and rural communities.

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96The Highly Specialised Drugs Program is delivered pursuant to section 100 of the National Health Act 1953 (Cth).
97Ms Annie Madden, Executive Officer, AIVL, Sydney hearing, 2 August 2001.
98HCC NSW, Submission No. 80.
99NUAA, Submission No. 68.
100HCC NSW, Submission No. 80, citing van Hattum, 5th International Hepatitis C Conference, Amsterdam November 2000.
101Dr Greg Dore, Sydney hearing, 3 August 2001.
102Ms Annie Madden, Sydney hearing, 2 August 2001.
103Ms Levinia Crooks, Sydney hearing, 3 August 2001.
105Currently, combination therapy represents best practice therapy, however, this may not be so in future. Accordingly, these recommendations aim to ensure that people have access to best practice therapy, whatever that may be in future.
Lack of knowledge of hepatitis C

Submissions to the Enquiry have raised concerns regarding health care workers’ lack of knowledge about hepatitis C.

I’m not surprised that some general practitioners…are still to grapple with some of the subtleties of testing, transmission, management and treatment. This is an evolving area. There are persistent “grey zones” in our knowledge about this condition - issues of best practice in testing, transmission, management and treatment are not all black and white.\textsuperscript{100}

While it is important to note that knowledge about hepatitis C is constantly evolving, many of the examples of lack of knowledge on the part of health care professionals relate to basic information about hepatitis C transmission and testing. While mere lack of knowledge is not discriminatory, such experiences emphasise the continuing need for health care worker hepatitis C education initiatives.

My experiences in rural NSW with GPs were terrible. I have found I know much more about the disease than any GP I have every met…It is ignorance which breeds fear and discrimination, and the best way to counter it is through regularly updated education of health care workers, including management and governance levels, and the wider community.\textsuperscript{101}

A client revealed to her mother that she had been diagnosed with hepatitis C. The mother rang the family doctor to find out some information about hep C. The doctor gave her incorrect information about transmission of the virus and the mother consequently washes hand towels every morning, cleans up full-on, and makes the client feel like a leper.\textsuperscript{102}

There was a paediatrician recently who saw a woman who hasn’t got HCV, her husband has but is PCR negative. The paediatrician told the woman there was a chance the baby has HCV. He held this three month old baby down and did all those blood tests, six tubes of blood. The mother rang me distraught, you could hear the tension between her and her husband down the phone.\textsuperscript{103}

A woman was told by her doctor that under no circumstances was she able to breastfeed her child.\textsuperscript{104}

Legislative remedies

Coverage under NSW and federal anti-discrimination law

Evidence to the Enquiry indicates that it is common for a person with hepatitis C to be refused health services and treated less favourably, than a person who does not have hepatitis C, in the manner in which the services are provided. Generally, under both NSW and Commonwealth anti-discrimination legislation, health care providers cannot discriminate on the ground of disability, including hepatitis C, by refusing to provide a service or by offering unfavourable terms or conditions to a person with hepatitis C. The ADA provides that it is unlawful to discriminate against a person with hepatitis C in the provisions of goods and services, both by refusing to provide the service or in the terms on which the service is provided.\textsuperscript{106}

As outlined above, breaches of confidentiality may not constitute discrimination on the basis of hepatitis C per se, but such disclosure often leads to less favourable treatment.

Health care professionals are asked on a regular basis to assess people’s capacity to do certain jobs, usually by way of taking a medical history and conducting an examination. Where a health care worker insists on disclosing a person’s hepatitis C status in a medical report, health care workers may find themselves party to discrimination complaints on the basis of having aided and abetted an employer’s discrimination. The issue of pre-employment medicals is discussed in detail in the employment section of this report at section 2.4.\textsuperscript{106}

\textsuperscript{100}Professor Michael Kidd, Sydney hearings, 3 August 2001.
\textsuperscript{101}Individual Submission No. 15.
\textsuperscript{102}Health care worker, Newcastle hearing, 15 May 2001.
\textsuperscript{103}Health care worker, Sydney hearing, 3 August 2001.
\textsuperscript{104}Individual Submission No. 6.
\textsuperscript{105}Health care worker, Wollongong hearing, 9 May 2001.
\textsuperscript{106}ADA, sections 49B and 49M.
The evidence also indicates that it is not always easy to clearly identify or characterise people's experiences of discrimination as less favourable treatment.

I cannot look you in the eye and say: ‘When they found out I was HCV+ they did this or did that’…it was a very intangible thing, it was a shifting of mood, it was a shifting of attitudes but none the less it was very real.107

Many of the examples of discrimination in health care settings raise the interrelationship between discrimination on the basis of hepatitis C status and drug use, whether actual, past or assumed. Where a person is discriminated against on the basis of drug dependency or assumed dependency as a result of a health care worker becoming aware of the person's hepatitis C status, it is arguable that one of the reasons for the discrimination is the person's hepatitis C status, and as such it may be covered by anti-discrimination law.

When people experience discrimination on the basis of current, past or assumed drug dependency, coverage under anti-discrimination legislation remains unclear. This issue is considered in detail in section 2.2.

Health care complaints legislation108

The NSW Health Care Complaints Commission (HCCC) was established pursuant to the Health Care Complaints Act 1993 (HCC Act). The HCC Act provides an avenue for consumers to make complaints to the HCCC about health care practitioners and health care services. The HCC Act provides for a co-regulatory framework, whereby some matters are investigated by the HCCC and others are investigated by the relevant health professional registration body.

The HCCC's functions are:

- to investigate and conciliate complaints relating to health practitioners and health services made under the HCC Act
- to provide an independent mechanism for assessing whether the prosecution or disciplinary action should be taken against registered health practitioners
- independent mechanism for assessing whether prosecution or disciplinary action should be taken against registered health practitioners
- to pursue prosecution action in Tribunals and Professional Standards Committees
- to publish and distribute information on the complaints process and outcomes
- to monitor, identify and advise on trends in complaints and recommend policy changes.

A complaint to the HCCC may be made by anyone including:

- a person who has received a health care service or their nominee
- an observer who could be a friend, relative or fellow patient, concerned about the conduct of a health care practitioner or the treatment given to someone by a health care practitioner or health care service
- a person providing a health care service, such as a doctor, dentist or nurse
- a health care facility such as a public hospital or private nursing home
- professional associations, such as the Australian Medical Association or the NSW Nurses’ Association
- NSW health registration authorities, such as the Medical Board, the Nurses Registration Board or the Pharmacy Board.

Complaints may be made about anything to do with health care or a health care service in the State of New South Wales. For example, a complaint may be made about:

- an aspect of treatment including inadequate care, inappropriate behaviour, inadequate diagnosis, lack of consent, communication
- a hospital, a nursing home, a community health centre, a private clinic or any other place that provides health care
- the care and treatment received from a doctor, nurse, dentist, chiropractor or any other health care practitioner including alternative and other non-registered health care practitioners, such as acupuncturists, masseurs, naturopaths
- access to medical records, privacy, breaches of confidentiality, discrimination or other health rights the professional conduct of a health care practitioner.

108 Information about the role of the HCCC is adapted from the HCCC website. Further information about the HCC Act and the HCCC is available at <www.hccc.nsw.gov.au>.
Many of the examples provided to the Enquiry about discrimination on the basis of hepatitis C in the provision of health services may be covered by anti-discrimination and/or health care complaints legislation. Yet few complaints are lodged. The HCCC’s submission to the Enquiry reported that only three hepatitis C related health complaints had been made to the HCCC in the past year. Given the broad range of issues the HCCC can investigate, this suggests the need to examine the adequacy of individual complaint remedies to respond to discrimination. It also emphasises the need to ensure that community-based advocacy organisations have the capacity and resources to act as an effective interface between communities and the various complaint bodies to enable individuals to use complaint mechanisms. This is considered in detail in Chapter 4.

Models of care

Many of the submissions made to the Enquiry raise concerns regarding the lack of knowledge among health care workers about hepatitis C and the quality of health care provided to people with hepatitis C.

The NSW Parliamentary Committee’s Report considered the inadequacies of service delivery and appropriate responses to these concerns in some detail. The Parliamentary Committee heard evidence about the Hepatitis C National Shared Care Project and the National Hepatitis C Education Program for General Practitioners, and considered the role that education of GPs and shared care arrangements may play in improving the quality of health care provided to people with hepatitis C.

Evidence to the Enquiry indicates that there is support both for greater utilisation of shared care between primary care practitioners and specialists, and enhanced primary care to:

- improve the quality of health care and access to treatment for people with hepatitis C, particularly people living in regional and rural areas
- better integrate primary care services and the allied health, support and advocacy services provided by community and non-government organisations and public sector agencies, thereby improving the quality of care of people with hepatitis C.

Since the Parliamentary Committee’s Report, NSW Health has undertaken a review of hepatitis C care and treatment services in NSW and is developing a Hepatitis C Care and Treatment Services Plan 2001–2003.

Enhanced primary care

The Commonwealth Government introduced an enhanced primary care initiative which includes Enhanced Primary Care Medicare Benefits Schedule items. This enable GPs to undertake or participate in care planning in case conferencing for people with chronic conditions, who often have multi-disciplinary care. With the introduction of enhanced primary care Medicare benefits, there has been considerable work done to maximise the use of this model by GPs.

One of the things that we [ASHM] have included in the module (for GPs) on practice in HIV and HCV management is a discussion around enhanced primary care codes. There is scope for some creative use of those codes to try and facilitate for clients, perhaps in a longer term management setting, improved access to GP services. That’s going to involve the community sector and public agencies being far more involved with general practice to achieve that.

Training and education strategies

To be sensitive to rights issues, health professionals must be knowledgeable about human rights. Since few health professionals – even in the most governmental domain of public health – have received any formal educational training about human rights, there is a considerable risk that health professionals may inadvertently violate rights, or consent to their violation in the context of the work.

While anti-discrimination legislation provides remedies where individuals have been discriminated against and health care complaints legislation provides a mechanism for complaints about health services, education initiatives for health care workers have a critical role in reducing incidents of discrimination and unfair treatment.

109HCCC, Submission No. 102.
110Hepatitis C: The neglected epidemic, Chapter 8, sections 8.3 and 8.4 at pages 230–255.
112See for example resources developed by the Royal Australian College of General Practitioners to maximise use of the model, Enhanced Primary Care: Standards and Guidelines for the Enhanced Primary Care Medicare Benefits Schedule Items.
113Ms Levinia Crooks, Sydney hearing, 3 August 2001.
The NSW Hepatitis C Strategy recognises that appropriate training and education of health care workers has the potential to significantly improve the effectiveness of prevention programs, and access to and the quality of care and treatment services available to people affected by hepatitis C. The Strategy specifically recognises that one of the key objectives of health care worker training and education is to reduce the discrimination faced by many people with hepatitis C or those at risk of infection. The Strategy commits NSW Health to a range of activities to improve the knowledge of health care workers and the quality of care provided to people with hepatitis C through improved access to training and education for health care workers. The Strategy requires that discrimination issues are addressed in NSW Health funded hepatitis C training and education programs.

While knowledge of hepatitis C transmission and treatments is important in improving the quality of health care provided to people with hepatitis C, it is clear from evidence to the Enquiry that training must enable health care workers to examine their values, attitudes and myths about hepatitis C transmission, people who have hepatitis C and those most at risk of infection.

It is possible that education and information and prejudice coexist. It may therefore be useful to make health care workers aware of their own values and attitudes and how this may impact on their work and interactions with clients. This...requires time and consequently money. The NSW Parliamentary Committee's Report considered health care and GP education and training issues in some detail. It is not within the scope of this Enquiry to examine in detail the breadth and effectiveness of hepatitis C related education initiatives for health care workers and GPs. Some current initiatives are considered and recommendations are made regarding the nature of education and training initiatives, and the resources and structures necessary to support effective and sustainable programs.

Health care worker education

NSW Health has funded the Hepatitis C Workforce Development Project to enhance the capacity of existing service networks to appropriately develop coordinated hepatitis C related responses. The project's objectives include facilitating workforce learning and development within organisations, and optimising health outcomes by building the capacity of Area Health Services. One of the significant benefits of this kind of model is sustainability.

Education and training are far more likely to be effective and sustainable when they:

- emphasis continuous learning, rather than one-off training sessions
- integrate individual learning needs, work-based activities, organisational structures and professional partnerships
- are clearly linked to organisational strategic outcomes.

Such an approach reflects NSW Health’s commitment to workforce development, which is defined as:

A process initiated within organisations and communities in response to identified strategic priorities, to help ensure that people working within these systems have the capacity to contribute to organisational and community goals.

Nonetheless, it is important to note that training and workforce development are to be achieved within Area Health Services’ existing resources. The reality is that creating opportunities for workplace learning is difficult in health service environments. The delivery of training is often fragmented and the need to release staff from service delivery makes it difficult to ensure that people have access to training and work development activities. Given this, it is critical that education and training for health care workers forms part of an integrated approach to hepatitis C service delivery by Area Health Services, and that there is clear commitment by Area Health Services and service management for workforce development.

The Hepatitis C Workforce Development Project primarily focuses on health care workers who are regularly in contact with people who have injected or do inject drugs, such as needle and syringe program workers and drug and alcohol workers. This is entirely appropriate and likely to improve the quality of care to people with hepatitis C. However, evidence to the Enquiry demonstrates that poor understanding and implementation of standard infection control, lack of knowledge about hepatitis C and negative attitudes towards people with hepatitis C are more likely to occur among health care workers in mainstream health care settings such as hospital and general practice. This emphasises the need for hepatitis C education and training for a wide

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116 TRAIDS — Medically Acquired HIV and HCV Counselling, Advocacy and Support Service, Submission No. 61.
range of health care workers, not limited to those specifically working in needle and syringe programs, drug and alcohol services, or hepatitis C-specific health care services.

The *National hepatitis C resource manual* was launched in September 2001. The manual includes information about anti-discrimination legislation and strategies to reduce discrimination in the health setting. The Australian Institute for Primary Care has been funded to implement the manual and a series of workshops were conducted during October and November 2001. The health care workers targeted for the training include needle and syringe program and drug and alcohol program workers, as well as nurses.

Evidence to the Enquiry demonstrates that there is a need for both undergraduate hepatitis C education and ongoing mandatory hepatitis C education for all nurses. It is critical that such education enables nurses to examine their values, attitudes, stereotypes and myths associated with hepatitis C transmission, people with hepatitis C and those most at risk of infection, particularly people who inject drugs, and to understand their obligations under anti-discrimination law. The Enquiry is of the view that that mandatory hepatitis C education for nurses should ensure that participants are assessed on:

- knowledge of and skills in pre and post counselling
- knowledge of hepatitis C transmission
- knowledge of standard infection control procedures
- understanding of the rationale for standard infection control procedures
- understand their obligations under anti-discrimination law.

A national review of nursing education (the Review) was announced in April 2001. The Review is being jointly conducted by the federal departments of Education, Training and Youth Affairs and Health and Aged Care. The Royal College of Nursing, Australia, (RCNA) in their submission to the Review, indicate that most nurses would embrace the opportunity for ongoing professional education. However, the RCNA state that this enthusiasm is quickly dampened when it becomes clear that the increase in education offers them little or no increase in remuneration or other rewards or incentives. The Enquiry supports that need for increased opportunities for continuing professional education for nurses.

### General practice - continuing medical education

Evidence to the Enquiry demonstrates that there is a need for undergraduate hepatitis C education and ongoing hepatitis C education and training for GPs. It is critical that such education enables GPs to examine their values, attitudes, stereotypes and myths associated with hepatitis C transmission, people with hepatitis C and those most at risk of infection, particularly people who inject drugs, and to understand their obligations under anti-discrimination law. There is inadequate evidence before the Enquiry to determine to what extent, if any, GP education programs to date have incorporated information about GPs’ obligations as service providers under anti-discrimination law and provided assistance to GPs to implement non-discriminatory policies and practices to support compliance with anti-discrimination law.

A disincentive to hepatitis C-specific education for GPs is that hepatitis C is only one of many diseases and conditions that GPs have to deal with and it often only comprises a small part of most general practices. Improved integration of hepatitis C education with related disciplines may prove valuable in encouraging participation. The costs associated with time out from service delivery and the accessibility of training programs, both in terms of the distance required to travel to attend and the times when courses are scheduled, impact upon the accessibility of such educational initiatives.

Generally, the Commonwealth Government has responsibility for funding education and training initiatives for GPs. The Parliamentary Committee considered in detail the National Hepatitis C Education Program for General Practitioner sponsored by the Royal Australian College of General Practitioners.

The program aimed to:

- develop a sustainable and coordinated infrastructure and policy that defines and supports the primary role of GPs in the long-term shared care of hepatitis C positive patients in collaboration with other health services
devise appropriate programs, services and resources to support the role of GPs in the provision of care to hepatitis C positive patients develop and implement appropriate vocational training and undergraduate education on hepatitis C.

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119. Submission to the National Review of Nursing Education, Royal College of Nursing, Australia, undated. The submission is available at <www.rcna.org.au>.
As part of this program, a hepatitis C management guide for GPs was produced in the form of a special edition of the Royal Australian College of General Practitioners journal. However, the Enquiry understands that this education program was not completed and some funds for resource development were diverted to ASHM. ASHM is currently developing hepatitis C resources for nurses, dentists and paramedics, as well as GPs, including internet-based resources. ASHM manages the NSW Health funded HIV/HCV Continuing Medical Education Project. ASHM's continuing medical education program is an accredited Royal Australian College of General Practitioners' course and ASHM works in partnership with the College, organisations such as the Rural Health Education Foundation and participating GPs in the design and delivery of their educational programs.

ASHM has developed and delivered continuing medical education by innovative means, such as satellite broadcasts, which aim to reduce the disincentives to GPs accessing training. The satellite broadcast on hepatitis C testing and management has also been reproduced as a video. The programs are continually updated and now integrate a range of information about hepatitis C, drugs and alcohol, and mental health in response to the needs of participating GPs. Peer-driven initiatives, coupled with a system of accreditation, also create greater incentives for GPs to participate in such education programs.

Education and training recommendations

The Enquiry recommends that:

18. NSW Health, in conjunction with Area Health Services, ensure that health care worker hepatitis C education and training forms an integral part of Area Health Services’ hepatitis C Strategies/Service Planning.

19. NSW Health ensure that adequate funding is made available to Area Health Services to address the hepatitis C education and training needs of all health care workers.

20. Area Health Services allocate adequate resources for hepatitis C education, training and workforce development that encourages continuous learning, is integrated within management systems and linked to organisational strategic outcomes.

21. Area Health Services provide hepatitis C education, training and workforce development for health care workers that:

- enables health care workers to examine their values, attitudes, stereotypes and myths associated with hepatitis C transmission, people with hepatitis C and people who have injected or do inject drugs
- supports implementation of standard infection control procedures and confidentiality policies and procedures
- ensures health care workers understand and comply with their obligations under anti-discrimination, privacy and related legislation.

22. The National Review of Nursing Education examine existing opportunities for continuing professional education about hepatitis C for nurses and consider options for improving such opportunities.

23. The Ministerial Advisory Committee on Hepatitis ensure that the NSW Hepatitis C Treatment and Care Plan provides minimum standards for Area Health Services in the delivery of appropriate hepatitis C education, training and workforce development for all health care workers.

24. The following principles should guide the development and delivery of hepatitis C education and training for GPs. Education initiatives should:

- provide GPs with the opportunity to examine the values, attitudes, stereotypes and myths associated with hepatitis C transmission, people with hepatitis C, and people who have injected or do inject drugs
- include information about GPs’ obligations under anti-discrimination, privacy and related legislation
- assist GPs to implement non-discriminatory policies and practices, including standard infection control and confidentiality policies, which support compliance with anti-discrimination and privacy legislation
- integrate hepatitis C education with related disciplines actively involve GPs, people with hepatitis C and those affected by hepatitis C in design and delivery.

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121 ASHM expanded their continuing medical education programs to incorporate hepatitis C in late 1999.
25. Pre-service tertiary training and educational institutions develop and incorporate hepatitis C specific education, including a focus on anti-discrimination, into their curricula for people training as nurses, doctors, dentists and other health care professionals.

Conclusions

Discrimination in health care settings was the most commonly reported context for hepatitis C related discrimination. Evidence to this Enquiry demonstrates that such discrimination in health care settings is widespread and has significant ramifications for the health and well-being of people with hepatitis C. It undermines the relationship between people with hepatitis C and health care professionals, and can become a serious deterrent for people seeking health care. In order to effectively address hepatitis C related discrimination in health care settings a range of policy, legislative and educational responses are necessary.

Given the complexity of the issues raised in relation to discrimination in health care settings, detailed recommendations have been made following the discussion of a range of issues within the body of this section, rather than at the conclusion of this section. Recommendations in the body of the section cover policy and legislative reform in relation to hepatitis C testing, confidentiality and privacy, infection control, and education and training strategies. All the recommendations are also outlined in the executive summary.

2.4 Employment

Overview

Submissions made to the Enquiry indicate that employment is the most common setting for hepatitis C related discrimination, after health care settings. Where a person’s hepatitis C status is disclosed, whether voluntarily by the person themselves, inadvertently by virtue of illness or treatment, or as a result of breaches of confidentiality by others, discrimination often follows. Relationships with colleagues can change following disclosure, sometimes leaving people isolated. Workplace-based discrimination can have devastating financial, social and emotional consequences.

Discrimination in the context of employment takes many forms. People with hepatitis C have lost their jobs as a result of their status or presumed drug use. Evidence indicates that discrimination occurs in the selection and recruitment process, for example, the inappropriate use of pre-employment medicals, requirements for testing and disclosure of a person’s hepatitis C status. Such workplace policies and practices also dissuade people with hepatitis C from proceeding with their application. Evidence also suggests that some employment agencies discriminate against people in the manner in which they provide employment services to people with hepatitis C, affecting people’s capacity to secure employment. The interrelationship between discrimination on the basis of hepatitis C status and discrimination in relation to drug use, whether actual or presumed, is particularly evident in the incidents relating to discrimination in employment.

Examples of discrimination detailed in submissions to the Enquiry include:

- termination of employment
- harassment by employers and co-workers
- inappropriate infection control strategies
- difficulties in negotiating access to their legal entitlements, particularly sick leave
- people being required to produce evidence of their ‘fitness to work’ from a treating physician, merely because of their hepatitis C status, unrelated to any application for sick leave.

Disclosure and confidentiality

...workers struggle with their illness and its side-effects while trying to maintain a job, and may feel unable to seek support from their employer or colleague for fear of misunderstanding and discrimination.122

One of the major concerns people with hepatitis C have raised during this Enquiry is the importance of confidentiality. Many individuals have told the Enquiry they do everything they can to avoid disclosure to anyone, particularly people at work, because they fear they will be discriminated against. Their fears are justified given the consequences that often flow from disclosure of a person’s status.

Within one month of starting treatment I was made ‘redundant’. I hadn’t told my employer specifically what the treatment was for, but they knew it was a serious virus and probably guessed it was hep C. I had also left a photocopy of a newspaper article about hep C on my bosses desk for a few hours one day. I decided to not leave it with him but I’m certain he saw it although we never actually said anything about it to each other…He was nervous and defensive when discussing it [redundancy] with me. [I was told] I was being replaced by an ex-employee. I asked why they [were] hiring someone else to replace me if the position itself was redundant. My performance had never been an issue and at my last appraisal I was told I was doing a fantastic job.

I think it happened because I was very tired as a result of treatment and began coming in late and leaving early. I explained to my boss that the treatment I was on had severe side effects and that I wasn’t sure how long it would take my body to adjust. Rather than discussing the situation with me he spoke to his boss and that would take my body to adjust. Rather than discussing the situation with me he spoke to his boss and the decision was made from there…No attempt was made to manage the situation. I felt that it was manageable and that as long as I met all my responsibilities that we could come to some sort of arrangement…I felt they deliberately didn’t mention my health or my treatment because they knew it was discrimination.

Breaches of confidentiality in the employment setting appear to be commonplace. Disclosure of a person’s hepatitis C status in employment can come about by a variety of means. Some people indicate that they have disclosed their status in order to enable them to negotiate their work hours to accommodate medical appointments or manage their treatment regime. Others indicate that the need to take time off for medical appointments or to manage their treatments can inadvertently result in their hepatitis C status being disclosed. There are examples of co-workers and employers disclosing peoples’ hepatitis C status in the workplace, often with devastating consequences for the individuals concerned.

A number of submissions outline the experiences of people being required to disclose their condition to the employer or harassed by their employer to disclose the precise nature of their health condition. Many people experiencing side-effects on anti-viral treatments persevere with their work commitments for fear that taking sick leave may expose their hepatitis C status and lead to discrimination.

The NSW Hepatitis C Council has undertaken a review of twenty four government and two non-government agencies’ policies, guidelines or protocols regarding hepatitis C specifically, or blood-borne viruses generally, in relation to their disclosure or management in the workplace. The HCC sought to establish what was in place, either in policy or in practice, when staff or clients of the agency disclosed, either voluntarily or through being required by workplace policy or practice, their HCV or other BBV status. The aim was to identify those agencies where either discriminatory policies or practice, or policies or practice that did not reflect best practice, with the intention reporting on the survey to this Enquiry, as well as work with those agencies to assist them to improve their policies and practices. The HCC report that generally, government agency policies relating to HIV/AIDS were well thought through, comprehensive and sensitive to the needs of people living with or affected by HIV/AIDS. In contrast, policies and procedures relating to viral hepatitis, and in particular hepatitis C, were ad hoc, often incomplete, sometimes contained incorrect information and in many cases were completely absent.

Specifically the HCC found that some policies and written protocols, where they exist for hepatitis C, are relatively good. Some agencies are in the process of reviewing and updating their policies.

One major are of concern they identify is that even where written policies or guidelines exist, poor implementation or are not implemented in practice.

For example, Safe Food Production NSW, a NSW Government organisation, has a good, rational policy and procedure governing the production and handling of food that is in line with legislation and formal guidelines. In summary, the Australia New Zealand Food Authority requires people who have a food-borne disease not to handle food when working in the food industry, or in some circumstances to take all practicable precautions to prevent food contamination. However, a senior occupational health and safety officer with Safe Food Production NSW advised the Council that all people with any infectious disease cannot handle food, not just those people with infectious diseases that are food-borne. We have concerns that this incorrect policy guidance would also be given to staff and others in the industry, and thus lead to discriminatory practice.

The HCC reported concerns regarding various government agencies policies and procedures including:

- The relevant COMCARE guidelines, governing the Australian Public Service, and the relevant policy of the Commonwealth Department of Employment, Workplace Relations and Small Business cover HIV, but not hepatitis C.

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123 Individual Submission No. 65.
124 Central Sydney AHS, Submission No. 19.
The NSW Department of Community Services (including Department of Ageing and Disability) has a specific policy on viral hepatitis A, B, C, D and E but information concerning hepatitis C is confusing. For hepatitis B and C the policy states that “Minimum period of exclusion from work: Can return to work on presentation of a medical certificate, which states that staff member is fit to return for work.” Contrast this with the HIV section that states “No person is to be excluded from working or entering Department premises because they are diagnosed as having AIDS/HIV.”

Department of Education and Training policy contains inaccuracies.128

Termination of employment

The Enquiry has heard examples of people with hepatitis C being dismissed from their employment when their status becomes known, or when an employer makes assumptions about a person's status or drug use. In other cases, the working environment becomes so difficult for the individual concerned, that they feel they have no choice but to leave. This is known as 'constructive' dismissal. Loss of employment in such circumstances markedly affects peoples' self-esteem and undermines their confidence in seeking employment.

A number of people have complained about discriminatory behaviour in the workplace, mainly from fellow workers, and in some cases this has led to employees leaving the workplace rather than face ongoing harassment.

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127 Individual Submission No. 86.
128 This is considered in detail in section 2.8.
129 Hepatitis C Council of South Australia, Submission No. 75.
case study

‘Mary’ was employed as a chef in a busy restaurant. She had been experiencing bouts of intense fatigue as a result of hepatitis C and her liver function tests indicated some liver damage. Mary was confident that she was a valued employee as she was often given positive feedback by her manager, the head chef. As a result, she disclosed her hepatitis C status to her immediate manager, the head chef and the restaurant manager. She decided she would disclose her hepatitis C status to her employer, so that they were aware of her circumstances, should she need to take time off work as a result of ill health or rearrange her shifts to attend medical appointments. She was subsequently sacked from her job. The reason given was that the restaurant was quiet over the January period. Some weeks later a friend, who had subsequently become a manager at the restaurant, told her that one of the reasons given to her employer was that she was a drug addict.

Nothing in my demeanour or conduct could have been read as someone affected by drugs as I was not using. The only way he could have come to this conclusion is because I have hep C. For the first time I became very paranoid about my illness and have not disclosed to anyone I work with in my new job that I have hep C. I believe that my employer made an assumption that because I had hep C that I was an IV user [intravenous drug user]. While this was true in the past, it’s not the case now. 130

Testing and pre-employment medicals

Evidence to the Enquiry indicates that discriminatory selection and recruitment policies and practices are of significant concern to people with hepatitis C, and impact upon their access to employment. The two areas of major concern are mandatory requirements for prospective employees to have a blood test or disclose their hepatitis C status, and the inappropriate use of pre-employment medical assessments to ‘screen out’ prospective employees who have hepatitis C.

I went for a job interview at the local meat works, my friend works there and the job interview went well… they said I should start in a couple of days and gave me a form to fill out… the form had many questions… and I told the truth on the hepatitis C question… they called me saying don’t bother showing up for the job we changed our mind… my friend told me this was because of the hepatitis C… he said that now everyone knew and they were scared of me because blood spills are common… I told him that with a proper health and safety system this is not a problem… always use gloves… I even called the employer and said I can prove it’s not a problem. 132

A woman was facing a dilemma of whether or not to answer a question on an employment application form that asked about hepatitis C. She didn’t want to lie but felt sure that if she was honest the chances of her getting the job would be jeopardised. 133

Where prospective employees are asked to have a blood test or disclose their hepatitis C status in their application for employment, people often believe they are under an obligation to disclose or to be tested. Generally, this is not the case and requiring a person to take a hepatitis C test may constitute direct or indirect discrimination on the ground of disability. Compulsory testing is only legal in rare situations. There are some very limited circumstances in which testing or knowledge of one’s hepatitis C status is required, for example, health care workers in NSW involved in exposure prone procedures are required to know their hepatitis C status. While it is recommended that health care workers with hepatitis C disclose their status to their employer, it is not mandatory to do so. This is discussed in more detail below.

In the Australian Hepatitis Council’s experience, people with hepatitis C often do not proceed with applications for employment if hepatitis C testing or disclosure are required, for fear that disclosure will lead to discrimination in the future or that they will not get the job. These mechanisms act as a barrier to people with hepatitis C gaining employment. Where they do apply, and choose not to disclose their hepatitis C status, they often worry about the legal implications, believing, incorrectly, that they are required to disclose and worrying they will subsequently be ‘found out’.

Pre-employment medical assessments are a relatively common part of recruitment practice. The use of pre-employment medicals is not necessarily discriminatory per se, however they may be used to discriminate depending upon when the information is sought, the type of information sought and whether the information obtained is relevant to the inherent requirements of a particular position.

In order to comply with anti-discrimination legislation, pre-employment medicals should only be used to assess a person’s capacity to carry out the inherent or essential requirements of a position, once the employer

130 Individual Submission No. 22.
131 Examples include: National Drug and Alcohol Research Council, Submission No. 59; AHC, Submission No. 60; Health care worker oral evidence of Council’s policy of mandatory blood test for prospective employees, HCC NSW, Submission No. 80; SWOP, Submission No. 53.
132 Hepatitis C Helpline (Victoria), Submission No. 54.
133 Hepatitis C Helpline, HCC NSW, Submission No. 80.
has identified the preferred candidate. Where the preferred candidate has a disability such as hepatitis C, the employer is required to accommodate the needs of the person to enable the person to carry out the inherent requirements of the job, unless they can demonstrate that this would cause the employer unjustifiable hardship.

The evidence indicates that pre-employment medicals are often required of prospective employees prior to culling candidates for interview. For many people with hepatitis C, pre-employment medicals raise the possibility of unfair culling or rejection because they have hepatitis C. Such an approach leaves employers open to allegations of discrimination, where they fail to appoint a person with hepatitis C. Pre-employment medicals also create a deterrent effect for prospective employees who have hepatitis C when testing or disclosure is required.

**Lack of understanding of hepatitis C**

Unfounded fears about hepatitis transmission often drives discriminatory conduct in workplaces.

A number of State-based Hepatitis C Councils report that they commonly field calls from employers in the hospitality industry which suggests that discrimination against people with hepatitis C appears to be particularly common in that industry.134

Is it legal to refuse someone with hepatitis C a job in the food industry?…oh it’s not like hepatitis A…oh only blood into another person’s bloodstream…OK but what about when blood is spilled at work?…yes I know I need to provide good health and safety equipment and training… but what if… but what if… I refused a girl a job because she had hepatitis C?… are you sure that is illegal?… Okay… so how do you think she got it then?135

It is clear that confusion still exists between the different modes of transmission for hepatitis A and C. While hepatitis A can be transmitted through food handling, employers often incorrectly believe that people with hepatitis C are legally prohibited from handling food. Such experiences have also been noted in relation to prisoners with hepatitis C being denied work in correctional facility kitchens.136 A number of reports have been received about Centrelink staff diverting people with hepatitis C away from positions in the hospitality sector.137

A food inspector working in regional NSW acknowledged people with hepatitis C were not excluded from working in food handling but said he could understand why a butcher in a small country town would have to sack a shop assistant if that person’s HCV status became known in town.138

Hepatitis C is not classified as a sexually transmissible disease. While sexual contact is not dismissed as a route of transmission, studies suggest that the risk is extremely low and such a risk is limited to where blood-to-blood contact occurs during sexual activity. The Sex Workers Outreach Project (SWOP) reports that sex workers who have hepatitis C have been refused employment or dismissed from employment on the basis of their hepatitis C status.139

Confusion and misplaced fears about disease transmission can lead to inappropriate responses in the workplace in the name of infection control.

One day when I went to get my mug I could not ignore the fact that my coffee mug was standing all on its own….During this particular year I developed an upset stomach and diarrhoea… Eventually the truth came out… (A co-worker) advised all to wipe over everything I came into contact with, with bleach, and to soak all food utensils in bleach. It was bleach residue I had been consuming with the coffee that had made me quite sick.140

Employers in NSW are required to comply with the WorkCover Authority of NSW’s *Code of Practice: HIV and other blood-borne pathogens in the workplace.* Under OH&S law, the Code has legislative force and can be used in proceedings as evidence that a person or company has failed to comply with the Act or Regulations.

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134 Examples include: case studies from the Hepatitis C Helpline (Victoria), Submission No. 54; Hepatitis C Council of South Australia, Submission No. 75 and HCC NSW, Submission No. 80.
135 Hepatitis C Helpline (Victoria), Submission No. 54.
137 Examples include: AHC, Submission No. 60 and Options Employment Service, Submission No. 89.
138 Hepatitis C Helpline, HCC NSW, Submission No. 80.
140 SWOP, Submission No. 53.
141 Individual Submission No. 8.
142 Code of Practice: HIV and other blood-borne pathogens in the workplace, WorkCover Authority NSW, 10 March 1996.
The NSW Hepatitis C Council has undertaken a review of twenty-four government and two non-government agencies’ policies, guidelines or protocols regarding hepatitis C specifically, or blood-borne viruses generally, in relation to their disclosure or management in the workplace. The Hepatitis C Council of NSW report that from the selection of agencies with whom they consulted, the majority do not comply with the Code’s requirements in respect of hepatitis C. They also report that generally the WorkCover Authority of NSW’s Code of Practice: HIV and other blood-borne pathogens in the workplace is a relatively complete and satisfactory code of practice, but it does require amendment in a number of areas in order to fully cover hepatitis C transmission, prevention, information and education.

Approximately 40% of people in NSW who have been exposed to hepatitis C are unaware of their status. Given this, and leaving aside the damaging consequences of disclosure of a person’s hepatitis C status, implementing infection control measures on the basis of assumptions or knowledge about a person’s hepatitis C status would be ineffective in reducing the risk of transmission. The rationale for and importance of appropriate infection control measures has been considered in more detail in section 2.3 above.

Evidence also indicates that some employment agencies do not understand that the impact, if any, of hepatitis C on a person’s capacity to work, can vary significantly from person to person.

One client was in a smaller town where there is very high unemployment. She recently went in [to Centrelink] to put in her usual form for unemployment and was told ‘we’ve organised for you to go on a pension now. We know that you’ve got HCV and that you’ve been on the methadone and that you’re a drug user.’ She was quite taken aback, this wasn’t her request, she was actually someone who wanted to work but had never really had the opportunity to have a career and education. Now that her daughter was grown she was wanting to get into the workforce. She is only in her mid-thirties.

Health care workers with hepatitis C

Many calls to Hepatitis C Councils concerning the health services sector during 2000 have been in relation to discrimination against HCV positive health care workers by other health care workers — most often nursing staff in public hospitals.

The importance of confidentiality in employment applies equally to health care workers with hepatitis C as evidence indicates that they commonly experience discrimination as employees within the health system.

As noted above, there are a number of specific policies in place regarding health care workers with blood-borne viruses such as hepatitis C. These policies aim to balance the rights of health care workers with blood-borne viruses and the health care system’s common law duty of care for all patients. The NSW Health Department’s circular Health care workers infected with HIV, hepatitis B or hepatitis C (the policy) is consistent with the need to ensure that health care workers with hepatitis C are not discriminated against in their employment, while at the same time ensuring the safety of patients.

The policy notes that there is a very low risk of transmission of blood-borne viruses from health care worker to patient, however there is some limited evidence to suggest that hepatitis C can be transmitted from health care worker to patient during exposure prone procedures. The policy defines exposure prone procedures as ‘procedures where there is potential for contact between the skin (usually finger or thumb) of the HCW and sharp instruments, needles or sharp tissues (splinter/pieces of bone/tooth) in body cavities or in poorly visible, confined body sites including mouth’.


— AHC, Submission No. 60.

— Individual Submission No. 63.

— For example: Australian Dental Association (NSW Branch), Submission No. 16 and Sussex Street Community Law Service and Hepatitis C Council of WA, Submission No. 72.


— Health care workers infected with HIV, hepatitis B or hepatitis C, Circular 99/88, at page 2.
The policy recommends that generally health care workers know their HIV, HBV and HCV status, although employers should not require evidence of their status. Regular testing is not recommended, nor justified, for health care workers who do not perform exposure prone procedures, given the very low risk of occupational transmission if standard infection control precautions are applied. However, health care workers who perform exposure prone procedures must know their status and employers must ensure that employees who perform exposure prone procedures have access to confidential testing and counselling. Health care workers who are infectious must not perform exposure prone procedures. In the case of hepatitis C, ‘infectious’ means health care workers who are HCV PCR positive as distinct from HCV antibody positive. While it is recommended that health care workers disclose their infectious status, it is not mandatory. Nonetheless, where a health care worker with hepatitis C performs exposure prone procedures they will usually need to negotiate changes to their duties and this will invariably involve disclosure of their hepatitis C status.

In order to comply with anti-discrimination legislation, it is essential that health care workers with hepatitis C are given the opportunity to continue in their field of work where practical or access retraining or transfers consistent with their skills and experience.

All NSW health services are required to comply with the policy and it is intended as a basis for each Area Health Service to develop detailed policies relevant to their particular settings. It is also recommended that professional organisations and private health services use the circular as the basis of their policy development. Such an approach is reflected in the guidelines of other organisations such as the NSW Medical Board.

The Australian Dental Association (NSW Branch), in their submission to the Enquiry, indicate that they strongly support and encourage their members, through regular education programs and provision of resources, to adopt universal infection control measures. However, the Association also raises concerns regarding the obligation of dentists with hepatitis C to refrain from exposure prone procedures, when this has the effect of precluding them from working. Further, they raise concerns that while these obligations exist for dentists, there are no comparable obligations on patients to disclose their status. Whether such a restriction is unlawful under anti-discrimination law is considered immediately below. However, it is important to address the distinction between health care workers with hepatitis C being required to be aware of their status and obligations on patients to disclose their hepatitis C status. Dentists perform exposure prone procedures numerous times on a daily basis and, as with all health care workers, they owe a duty of care to their patients. On the other hand, knowledge of a patient’s status does not alter the need to provide standard infection control in all cases, because patients will not necessarily know their status. Knowledge of patients’ status can lead to the false assumption that it is possible to minimise the risk of infection based on knowledge of a person’s status. Given that approximately 40% of people are not aware of their hepatitis C status, this is clearly not a safe assumption.

The ADA and the DDA provide specific exceptions in relation to discrimination on the ground of disability, where the disability is an infectious disease and the discrimination is necessary to protect public health. It is arguable that the requirement that health care workers with hepatitis C and other blood-borne viruses do not undertake exposure prone procedures may not be unlawful under anti-discrimination law, given the specific exception relating to protection of public health. There is evidence, albeit limited, of hepatitis C transmission in the performance of exposure prone procedures. An employer would need to demonstrate that such evidence justifies the restriction of health care workers with hepatitis C from undertaking exposure prone procedures on the basis that it is reasonably necessary to protect public health.

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149 See Chapter 1, section 1.2 for the distinction between HCV antibody positive and HCV PCR positive.
150 Medical practitioners & blood borne viruses — HIV, hepatitis B and hepatitis C, NSW Medical Board, 1997. This document is currently being updated to bring the policy in line with NSW Health Circular 99/88.
151 Australian Dental Association (NSW Branch), Submission No. 16.
152 ADA, section 49P; a comparable section exists in the DDA, section 48.
Related occupational discrimination

Drug and alcohol workers within [the] health [system] are demoralised…I’ve heard comments: ‘Oh they’re all just ex-junkies’…they are…discriminated against because of the clients we help…there are lots of rumours and innuendos made about drug and alcohol workers by other health professionals and it happens on a fairly regular basis.\(^{153}\)

I’ve heard stories from health care workers where they’ve been discriminated against by the general public because they have been out in the field and talking to clients…they’ve been watched talking to these people and then later on have been refused to sit at a café because they are associating with undesirables…\(^{154}\) Health care workers employed in specific hepatitis C and drug and alcohol related positions or services such as needle and syringe programs have outlined many examples where they have been discriminated against within the health system and by prospective employers because of the nature of their work. In some cases the discrimination appears to be based on assumptions about the worker’s hepatitis C status or drug use. In such circumstances, anti-discrimination legislation may apply. However, in other examples raised, the discrimination appears to be directed at the nature of their occupation as a drug and alcohol counsellor per se. These examples point to a growing need for improved coverage under anti-discrimination law for people who are discriminated against on the basis of their occupation. The ADA is currently being reviewed and the ADB has indicated strong support for the inclusion of occupational discrimination as a ground under NSW anti-discrimination legislation.

Coverage under federal and NSW anti-discrimination law

As previously outlined, federal and NSW anti-discrimination laws prohibit discrimination against a person on the basis of their hepatitis C status, in specific areas of public life covered by the legislation, including employment.\(^{156}\) Both the DDA and the ADA prohibit disability discrimination in a wide variety of employment contexts including discrimination against commission agents and contract workers, and discrimination by local government councillors, industrial organisations and employment agencies.

It is unlawful for an employer to discriminate against an applicant for employment on the ground of their disability:

- in the arrangements an employer makes for the purpose of determining who should be offered employment
- in determining who should be offered employment
- in the terms on which the employer offers employment.

It is unlawful for an employer to discriminate against an employee on the ground of disability:

- in the terms or conditions of employment which the employer affords the employee
- by denying the employee access, or limiting the employee’s access, to opportunities for promotion, transfer or training, or to any other benefits associated with employment
- by dismissing the employee
- by subjecting the employee to any other detriment.

However there are exceptions which may apply. The most relevant of these permits discrimination in relation to recruitment or termination of employment where, taking into account factors such as the person’s past training, qualifications, expertise and performance as an employee, the person, because of his or her hepatitis C, would be unable to carry out the inherent requirements of the particular employment or would require services and facilities and the provision of these would impose unjustifiable hardship on the employer.

Generally, an employer is required to accommodate the needs of its employees and applicants. For example, an employee may need to arrange flexibility in their hours of work to attend medical appointments or to work from home in order to manage anti-viral treatment. Failure by the employer to make arrangements to enable an employee with hepatitis C to perform their work may be discriminatory, unless the employer can demonstrate that it would be unjustifiably harsh for him/her to be required to do so.

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\(^{155}\) Individual Submission No. 20.
\(^{156}\) ADA, Division 2, sections 49D–49K; DDA, Division 1, sections 15–21.
In the High Court case of *X v Commonwealth*,[157] involving alleged discrimination on the ground of HIV status, Justice McHugh determined that the defence of inherent requirements of the position and unjustifiable hardship must be read as a whole. When seeking to rely on such a defence the employer must show that the applicant or employee was not only unable to carry out the inherent requirements of the job without assistance but was also able to do so only with assistance that it would be unjustifiably harsh to expect the employer to provide.

Another exception which may be relevant in some instances, is the public health exception. It is lawful for an employer to discriminate against a person on the basis of their hepatitis C status where the discrimination is necessary to protect public health.[158] In order for employers to rely on this defence, they would need to prove that there was indeed a risk to public health. Clearly employers who deny people with hepatitis C employment in the hospitality industry, when there is no evidence that hepatitis C is transmitted through handling food, would be unable to establish any risk to public health and therefore would not be in a position to rely on this defence. On the other hand, it may be arguable that where employers prevent health care workers with hepatitis C from performing exposure prone procedures the exception may apply, given that there is evidence, albeit limited, of hepatitis C transmission in the performance of exposure prone procedures.

It is also important to note that, generally, employees are vicariously liable for the conduct of their employees unless the employer can demonstrate that they took reasonable precautions to prevent the employee or agent contravening the Act.[159] This places the onus on employers to ensure that their employees are aware of their obligations under anti-discrimination law.

Even taking account of the fact that the above exceptions may apply in some cases, it is arguable that a wide variety of issues raised in evidence to the Enquiry would be covered by anti-discrimination law including:

- termination of employment or refusal to hire a person on the basis of their hepatitis C status
- harassment on the basis of a person's hepatitis C status
- less favourable treatment such as refusing the person access to the staff kitchen
- inappropriate use of pre-employment medicals to cull or refuse employment to people with hepatitis C
- requirements that people disclose their hepatitis C status or undergo hepatitis C testing.

When a person is discriminated against on the basis of their hepatitis C status, such discrimination need only be one of the reasons for the alleged discrimination to bring the matter within the ambit of the ADA.[160] The mere fact that another reason was given, for example that the person was being made redundant rather than being sacked as a result of their hepatitis C status, would be a question of fact to be determined in any proceedings under anti-discrimination law.

Many of the examples of discrimination provided to the Enquiry raise the interrelationship between discrimination on the basis of hepatitis C status and assumed drug use. Where a person is discriminated against on the basis of drug dependency or assumed dependency as a result of the employer becoming aware of person's hepatitis C status, it is arguable that such discrimination arises because of the person's hepatitis C and as such would be covered by anti-discrimination law.

Where people experience discrimination on the basis of current, past or assumed drug dependency, coverage under anti-discrimination legislation remains unclear. This issue is considered in detail above: see section 2.2.

Despite extensive evidence of discrimination in employment settings, few complaints of hepatitis C related discrimination are lodged under the ADA or DDA. This is examined in Chapter 4.

### Other legislative remedies

Federal and NSW industrial legislation provide remedies for lawful termination of a person's employment. Employers are required to comply with OH&S legislation by ensuring that appropriate infection control practices are applied in all workplaces pursuant to the WorkCover Authority of NSW’s *Code of Practice: HIV and other blood-borne pathogens in the workplace*. As outlined above in relation to discrimination in health...

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[158] ADA, section 49P; a comparable section exists in the DDA, section 48.
[159] ADA, section 53; DDA, section 123.
[160] ADA, section 4A.
[161] As notes above, the WorkCover Authority of NSW’s *Code of Practice: HIV and other blood-borne pathogens in the workplace* does need to be revised and updated.
care settings, only rarely is mandatory or compulsory testing ever appropriate or lawful.\textsuperscript{162}

Many employers are also required to comply with federal and NSW privacy legislation: see Chapter 4 for a discussion of the adequacy of privacy legislation, proposed legislative reform and recommendations.

Conclusions and recommendations

The Enquiry concludes that hepatitis C related discrimination in employment is extensive and takes many forms, including selection and recruitment practices which deter people from seeking employment, loss of employment, and harassment in the workplace. Such discrimination often has devastating financial, social and emotional consequences.

It is clear that many employers do not understand their obligations under anti-discrimination law. Evidence indicates that many employers have an inadequate knowledge of hepatitis C transmission, the extent to which it is a risk in the workplace, and the rationale for standard infection control procedures. Hepatitis C education initiatives targeting key private and public sector employers are essential in order to address hepatitis C related discrimination in employment.

The Enquiry recommends that:

26. The WorkCover Authority of NSW update and reissue the \textit{Code of Practice: HIV and other blood-borne pathogens in the workplace}.

27. The ADB establish an advisory committee to develop and deliver a Hepatitis C Workplace Education Strategy to ensure an effective and coordinated response to hepatitis C related discrimination in employment. The advisory committee should include representatives from the NSW WorkCover Authority, NSW Health, the NSW Labor Council, Privacy NSW, and relevant community, employer and union representatives.

28. The Hepatitis C Workplace Education Strategy should include activities that support and promote:
   
   - effective implementation of appropriate workplace policies in relation to non-discriminatory selection and recruitment, in compliance with anti-discrimination law
   - adequate and appropriate workplace training regarding the rights and obligations of employers and employees under anti-discrimination law
   - effective implementation of appropriate workplace policies in relation to infection control, in compliance with the WorkCover Authority of NSW’s Code of Practice: HIV and other blood-borne pathogens in the workplace, as updated, and OH&S law
   - effective implementation of workplace policies on confidentiality and privacy, in compliance with privacy laws.

29. The NSW Government provide adequate funds for the development and implementation of the Hepatitis C Workplace Education Strategy.

30. The NSW Government amend the ADA to include discrimination on the ground of profession, trade, occupation or calling.

2.5 Custodial settings

Background

The Enquiry acknowledges the assistance of the Department of Correctives Services (DCS) in facilitating its visits to several custodial facilities and arranging for the Enquiry to take evidence from staff and inmates.

Figures as at May 2001 indicate that 7,500 people were incarcerated in NSW correctional facilities and a further 1,500 people were periodic detainees.\textsuperscript{163} Figures at a given point in time do not, however, reveal the rapid turnover of the NSW prison population, with approximately 17,000 people moving through the system each year. It is well documented that Aboriginal people are over represented in the Australian population.

\textsuperscript{162} National hepatitis C testing policy, ANCAHRD and the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases. This policy is currently in draft form and due for release in late 2001: see <http://www.ancahrd.org/index.htm>.

\textsuperscript{163} Department of Correctives Services, Submission No. 100.
correctional system. While the imprisonment rate for non-Indigenous Australians is 85 per 100,000, it is 1,790 per 100,000 for Indigenous Australians.  

A recent study has found that of more than 4,000 people tested in custodial settings in NSW, 62% of women and 46% of men were hepatitis C positive.\textsuperscript{165} Given the prevalence of hepatitis C in the NSW prison population, issues regarding access to health care generally, including anti-viral treatment and health promotion in the correctional system are of critical importance to prisoners with hepatitis C. This section focuses on these issues in particular.

It is well recognised that imprisonment is a potent risk factor for hepatitis C.\textsuperscript{166} We justify depriving people of their liberty for transgressing social norms on the grounds of protecting society or rehabilitating the person. However, in the case of illicit drug use, there is little evidence that either of these objectives is achieved by current approaches. Imprisonment exposes injecting drug users to greater risks of infection with blood-borne viruses, (such as hepatitis B and C), than in the community...About half of all injecting drug users have histories of imprisonment; about half of all prisoners have histories of injecting drug use; and about half of all imprisoned injecting drug users inject drugs in prison.\textsuperscript{167}

Many submissions to the Enquiry raised issues regarding the need to improve hepatitis C prevention strategies in custodial settings. Individuals are incarcerated for punishment, not as punishment, and they remain entitled to health care of a standard equivalent to that of the general community. Nonetheless, generally the community has access to essential hepatitis C prevention programs and services, such as needle and syringe programs and safe tattooing services, which NSW prisoners do not. A number of key reports in recent years have examined issues relating to hepatitis C prevention in NSW custodial settings and made recommendations. In particular, the Parliamentary Committee’s report, *Hepatitis C: The neglected epidemic*, examined the extent of hepatitis C infection among prisoners and the risks associated with hepatitis C transmission in custodial settings, and made recommendations in relation to hepatitis C prevention in NSW custodial settings.\textsuperscript{168} The National Drug and Alcohol Research Centre, in its report *Surveillance and prevention of hepatitis C infection in Australian prisons: A discussion paper*, has also given detailed consideration to preventative measures to reduce hepatitis C transmission in custodial settings.\textsuperscript{169}

While there is no doubt that reducing the number of people who contract hepatitis C will result in fewer people experiencing hepatitis C related discrimination in future, hepatitis C prevention initiatives are also essential to ensure that prisoners with hepatitis C are not exposed to reinfection. Prevention issues, however, do not fall neatly within this Enquiry’s terms of reference. Given this, it is not within the brief of the Enquiry to make specific recommendation on prevention issues. Therefore, this section of the report summarises the key issues raised in the evidence to the Enquiry in relation to hepatitis C discrimination in custodial settings. Where appropriate, the Enquiry endorses recommendations previously made in relation to these matters.

### Hepatitis C related discrimination in custodial settings

Given the significant proportion of prisoners with hepatitis C, many submissions identify that it is often difficult to distinguish between discrimination on the basis of drug use and hepatitis C status, and the challenges of delivering health care services within the correctional system. 

Hepatitis C discrimination has really been normalised into discrimination against prisoners in general...Pretty much all prisoners are treated really, and with statistically reasonable grounds, as if they’re hepatitis C positive, these days...If they stick their hands up and say, ‘I want bleach’, they’re likely to get cell searches, they’re likely to have their visitors searched, and they won’t complain about, you know, ‘I’m being


\textsuperscript{168} *Hepatitis C: The neglected epidemic*, see section 3.1, pages 68–80 and section 10.2, pages 341–381.

discriminated against because I’m hep C positive, and I don’t want to infect my friends’, they’ll be discriminated against because they’ll ask for bleach and therefore implied ‘I’m an IV drug user’.170

However, a number of submissions reported specific incidents of discrimination related to a prisoner’s hepatitis C status, including the issue of prisoners being refused employment in prison kitchen facilities on the basis of their hepatitis C status.

I’ve had numerous incidents where inmates have asked to work in the [staff kitchen], if that’s where the position was available, and they were suitable only that staff didn’t want them working there because they had hep C…they say well if this person has hep C, I don’t want them preparing my food…So that’s a huge problem I think for inmates who’d like to get work.171

This echoes the misinformation about hepatitis C transmission and the discriminatory experiences of people with hepatitis C considered above in relation to discrimination in employment settings: see section 2.4.

Another submission outlined a case where a prisoner was not allowed to play football because of his hepatitis C status.172 The Enquiry also received examples of the difficulties people with hepatitis C have experienced in bringing hepatitis C medication into jail, appropriately storing the medication within jail and getting timely access to the medication.173

I need vitamins to preserve what little health I have, but my wage doesn’t give me enough money, and accessing programs is really difficult with most of us HCV positive…then there’s the fact that more and more women become HCV positive every week…with all the sharing going on in these places you think they’d have needle exchange for sure.174

Access to health care

Responsibility for the health of prisoners in NSW is shared by the Department of Corrective Services (DCS) and the Corrections Health Service (CHS). The DCS has responsibility for providing drug and alcohol counselling, prevention education, and some HIV and hepatitis C health promotion programs. The CHS is an independent health service, funded through NSW Health, which provides clinical and health promotion services to inmates within the NSW correctional system. While both the CHS and DCS have distinct areas of responsibilities in relation to the health of prisoners, there is some overlap with respect to health promotion and prevention services and programs.

Many of the problems prisoners with hepatitis C experience in the correctional system are not particular to prisoners with hepatitis C, but relate to the delivery of health services within the correctional system. The capacity to provide standardised care in the prison environment is characterised by overlapping administrative, security, disciplinary and health considerations. Many of the problems prisoners with hepatitis C face are systemic problems rather than failures or deficiencies in the provision of health care.175

A great many challenges exist in relation to the general delivery of health care services to inmates within the correctional system. There is significant movement of inmates between prisons and the community, and between correctional facilities. The prison population turns over rapidly, with the majority of people imprisoned for periods between three and six months. Tensions exist between security requirements and the access of prisoners to health care services, irrespective of where such health services are within or outside of custodial settings. Often inmates have other health concerns, including drug and alcohol and mental health issues, which are identified as more significant by both the inmate themselves and CHS staff.

Our clients are sick when they come to jail…most of them have a mental illness or drug and alcohol problems, developmental disabilities…these are people who are often unable to access services outside and there is a perverse opportunity provided when they come to jail.176

Dr Michael Levy’s evidence to the Enquiry highlights the complexity of health service delivery in the correctional system.

There are something like 130,000 movements of prisoners, between prisons and court and between prisons per year. Now apart from the disaster that that is in terms of disease control, what that means for a person with hepatitis C that is undergoing a series of examinations, the results of which will come back days or
weeks later, and then maybe moving down a diagnostic and treatment pathway that will take months or longer. For a person who is going to be moved four, five, six times a year from place to place…you’d have to wonder what are the prospects of that person being able to be counselled, give consent, be tested, get their results, wait for the monthly hepatitis clinic, be staged for a biopsy, have the biopsy…the prospects are vanishingly small…There are systemic impediments to that even happening.177

In order to address the challenges of managing the provision of hepatitis C related health care services in an environment where it is common for prisoners to be moving between correctional facilities, the CHS is currently developing a continuum of care in relation to blood-borne viruses, particularly hepatitis C, supported by specific protocols, incorporating health promotion, prevention, services for newly diagnosed inmates, ongoing clinical management and discharge planning. The aim is to ensure a consistent and best practice standard of care for prisoners with hepatitis C. This approach also recognises the importance of integrating clinical services with health promotion and hepatitis C prevention programs. There is a recognition by CHS that implementation of this continuum of care must be supported by capacity building for generalist nursing staff, in addition to specialist public health nurses. Such an approach requires adequate resources to ensure effective implementation.

Evidence from both CHS staff and inmates indicates that there can be delays in prisoner access to visiting medical officers. This can be exacerbated when security arrangements prevent access on a day that the visiting medical officer is available. CHS employees describe the security challenges inherent in the correctional system:

At Grafton, the gaol has been locked down for 45 days this year. Inmates are not out of their cells for 45 days of the 150 that we’ve had this year. That means nobody gets to the clinic.179

Access to hepatitis C treatment

The standard therapy now used in the treatment of hepatitis C is interferon used in combination with ribavirin (combination therapy). Treatment outcomes for many people with hepatitis C are encouraging, although the side-effects of treatment can be severe and difficult to manage.180

The development of specialist hepatitis C clinics within the correctional system has improved hepatitis C health care in recent years. Specialist hepatitis C clinics are based at Long Bay complex, Silverwater complex, and Bathurst, Goulburn, Cessnock and Emu Plains correctional facilities.181 As is the case within the general community, only a small proportion of prisoners with hepatitis C require treatment. CHS estimates that in May 2001 approximately 20 inmates were receiving combination therapy. While there are challenges to ensuring prisoner access to combination therapy, the CHS emphasises that ‘…not one of those 20 had their treatment commenced outside. Every one of those 20 was initiated inside [jail].’182

A range of factors act as disincentives to prisoners accessing specialist clinics and/or combination therapy. Some of the factors regarding the duration of time prisoners spend in jail and movements of prisoners within the system have already been discussed above. An additional factor is the issue of access to facilities which perform liver biopsies. Currently, the requirements for prescribing interferon and ribavirin make a liver biopsy essential in order to consider initiating treatment. Facilities within correctional facilities for undertaking invasive procedures are limited and thus arrangements need to be made to transfer inmates to community health facilities to conduct the procedures.

The CHS’s submission to the Enquiry indicates that there are barriers to this occurring, ‘such as the willingness of hospitals to accept inmates for day only procedures and the capacity of the Department of Corrective Services to provide secure escorts to and from the prison…’.

177 Dr Michael Levy, Goulburn hearing, 8 May 2001.
181 CHS, Submission No. 31.
We have to get agreement from more Area Health Services for more base hospitals to accept prisoners for day only procedures and to broaden our capacity to initiate treatment…A community physician comes here and has identified up to 12 inmates who are eligible for biopsy and we have not yet been able to get Goulburn Base Hospital to accept those people.\textsuperscript{183}

When prisoners are transferred to a correctional facility with a specialist clinic, there may be long delays in accessing that clinic. Prisoners fear losing their cell, their employment and not returning to their original facility. Prisoners on complex treatment regimes such as combination therapy usually do not have access to remote prisons.

There tends to be a reticence both by [the] Corrections Health Service… and on the part of [the] Department of Corrective Services, that people on complex treatments don’t go to remote prisons. Now the remote prisons happen to be the ones that are nice to be at, the ones that are minimum security… these are places, much lower stress, much safer, you don’t tend to be shuffled around once you’re there… Therefore there is a disincentive for a person on a complex treatment. If they want to go to Glenn Innes or Tumbarumba, they will have to sacrifice that.\textsuperscript{184}

There is also emerging evidence in the scientific literature that indicates that liver biopsy may not be mandatory in order to determine whether treatment is indicated.\textsuperscript{185} This is of particular significance for inmates, given the difficulties associated with access to biopsy in custodial settings, and the extent to which this reduces inmates access combination therapy. The research indicates that biopsy does not change the clinical evaluation outcome in more than 30% of patients.\textsuperscript{186} While the information provided by biopsy is important, if treatment would be otherwise prevented by lack of access to biopsy, clinicians can determine who will benefit from therapy in the majority of patients by other means.

The Enquiry understands that this issue is being considered by the NSW Ministerial Advisory Committee on Hepatitis. The Enquiry strongly supports consideration of both this emerging evidence, and if appropriate, enable the use serological markers to assess liver damage and determine whether treatment for inmates is indicated, in order to maximise their access to hepatitis C treatment.

**Dietary issues**

A number of submissions raised concerns about access to low-fat foods for prisoners with hepatitis C.

I had one inmate ask about going on soy milk or skim milk and I asked one of the [Nurse Unit Manager] and his response was ‘he’s not showing any symptoms so we’re not putting him on it’.\textsuperscript{187}

The Enquiry also received evidence which presents a contrary view on this issue.

In terms of diet, I believe its better. It’s been assessed by professional nutritionists. The question always asked is about the fat content. The fat content has gone down. Whether that’s specifically because of hepatitis C, I have my doubts, because the advice that I’ve been giving them is that whether a person is hepatitis C positive or not, unless they’re in terminal liver failure, shouldn’t affect their fat tolerance. And that’s the advice I’ve received. So I don’t subscribe to the idea that hepatitis C or people with chronic hepatitis necessarily need a different diet.\textsuperscript{188}

The National hepatitis C resource manual states:

Although there is no evidence that improvements in diet have any direct virological effect, people with hepatitis C can optimise their nutritional status and their resistance to other infections through a healthy choice of food.\textsuperscript{189}

Nutritional considerations therefore should be the same for prisoners as for the general population, that is high fibre and low fat. Evidence to the Enquiry indicates that the DCS are engaged in an ongoing process of reviewing diets.\textsuperscript{190}

\textsuperscript{183} Dr Michael Levy, Goulburn hearing, 8 May 2001.
\textsuperscript{184} Dr Michael Levy, Goulburn hearing, 8 May 2001.
\textsuperscript{187} Health care worker, Lismore hearing, 23 May 2001.
\textsuperscript{188} Dr Michael Levy, Goulburn hearing, 8 May 2001.
\textsuperscript{189} National hepatitis C resource manual, page 106.
\textsuperscript{190} Dr Michael Levy, Goulburn hearing, 8 May 2001.
Access to health promotion and prevention education

It is well recognised that hepatitis C prevention and health promotion in custodial settings are of vital importance, given the high risk environment for transmission in correctional facilities, the high proportion of people who inject drugs and the high proportion of people who have hepatitis C moving through the correctional system and from prison into the community.¹⁹¹

The DCS has responsibility for the delivery of education regarding hepatitis C prevention and health promotion for inmates. Given the rapid turnover of the custodial population, as discussed above, ensuring effective prevention and health promotion in the correctional system is a challenge.

The NSW Parliamentary Committee’s report on hepatitis C examined issues relating to the adequacy of hepatitis C prevention and health promotion programs in custodial settings and made recommendations in relation to educational programs.¹⁹³ Specifically, the Parliamentary Committee recommended that:

- a review be conducted into the HIV and Health Promotion Unit to ascertain the staffing needs of the unit and to ensure that the unit is adequately resourced to meet the information and educational needs of hepatitis C inmates in the State’s correctional system
- the HIV and Health Promotion Unit ensure all educational strategies employed reflect current health promotion practices.

In response to these recommendations, the DCS has provided the following information regarding their hepatitis C prevention and health promotion programs since the Parliamentary Committee’s report:

- the Lifestyles Unit for women at Mulawa has been established and has been operational since July 2000
- the Alcohol and Other Drugs and HIV Health Promotion Units have since merged and the new unit has been subject to review processes carried out by an independent review team as per the Drugs Summit recommendations. In summary, DCS now has more centre-based staff to address the health and educational needs of inmates with hepatitis C
- in relation to educational strategies employed by the DCS, the DCS states this is an ongoing part of continued peer review and quality assurance.¹⁹⁴

The DCS’s HIV/AIDS communicable diseases and health promotion — policies and procedures and management guidelines detail education initiatives, and policies on testing, infection control, bleach program and confidentiality issues.¹⁹⁵ The DCS acknowledges that this resource is not currently up to date.¹⁹⁶

Evidence to the Enquiry indicates that there is inconsistent access to hepatitis C prevention information and education programs within the correctional system.¹⁹⁷ The ‘Lifestyles’ HIV/HCV health promotion programs are provided at Long Bay and Mulawa correctional facilities. The Lifestyle programs are intensive courses run for between 6–12 weeks. They include information about liver function, diet, life skills, stress management, drug and alcohol management, hepatitis C transmission, and provision of vitamins. Evidence to the Enquiry indicates there is significant support for these programs, but that access to these programs is limited.¹⁹⁸ Evidence also suggests that access to the program may be used as a management tool:

…..we get quite a few reports that the Lifestyles unit is used as a lever…..they’ve got a long waiting list for the healthy Lifestyles unit, virtually the slightest problem will get somebody bumped off that waiting list, any sort of a conflict, any sort of irregularity. This means that access to the program becomes a privilege rather than a right and [the/our] ability to reduce the chance of infecting others is greatly compromised.¹⁹⁹

The CHS also plays an important role in hepatitis C prevention and health promotion, as part of an integrated approach to the delivery of clinical services. Hepatitis C screening is offered by CHS clinics at all

¹⁹¹ NSW Hepatitis C Strategy at pages 9 and 11.
¹⁹² Dr Alex Wodak, Sydney hearing, 2 August 2001.
¹⁹³ Hepatitis C: The neglected epidemic, at pages 341–346.
¹⁹⁴ DCS, Submission No. 100.
¹⁹⁶ Personal communication, Alcohol and Other Drugs and Health Promotion Unit, DCS.
¹⁹⁹ Mr Michael Strutt, Sydney hearing, 2 August 2001.
correctional centres. Dr Michael Levy’s evidence to the Enquiry emphasises the significance of hepatitis C screening in prisons:

With this program of targeted screening, about 60% of inmates consent voluntarily to a range of screening based on their risk history, and of those who consent to hepatitis C screening, about a third are receiving the first hepatitis C result in their life.

CHS clinic services generally, and pre and post test counselling in particular, are a valuable opportunity to provide hepatitis C prevention and health promotion information. The CHS also provides some group services in relation to health promotion, however the evidence indicates there are ongoing challenges in relation to the CHS’s role in health promotion given that the CHS is not funded to provide health promotion services per se. As outlined in relation to health care, such one-on-one educational opportunities are difficult to provide in the prison environment.

In terms of [prevention] education…I’m expected to provide that to the 50 [new] inmates [per month], plus the referrals I get from other jails…plus the inmates that self-refer to my clinic as well. So I physically can’t see all…[in relation to] new receptions, what we’ve recently identified is that we really need to get to the inmates that are young, non-injecting and have never been tested for hep B, C or HIV because they’re so vulnerable…to blood-borne viruses.

The NSW Hepatitis C Strategy emphasises that a key principle of clinical treatment is that ‘all health services involved in the caring treatment of people with hepatitis C have an important role to play in minimising the further spread of infection.’

Access to the means of hepatitis C prevention

As outlined above, a number of key reports in recent years have made recommendations in relation to hepatitis C prevention in NSW custodial settings. This section summarises the key issues raised in the evidence to the Enquiry in relation to hepatitis C prevention in custodial settings. Where appropriate, the Enquiry endorses recommendations previously made in relation to these matters.

Access to injecting equipment

It cannot be said often enough that punishment is deprivation of liberty, and that is all. Prisoners should have available to them all the means for protecting themselves against infection with blood borne viruses that are available outside prison, without qualification.

There is overwhelming evidence that needle and syringe programs are effective in reducing hepatitis C transmission. The Enquiry has heard extensive evidence about the NSW government’s current policy that needles and syringes are not available in custodial settings and the need for them to be available.

The [prison] population’s important because it turns over rapidly…the prevalence of injecting in prisons is very high, in the community about 1% of the population injects; in prisons about 25% of the inmate population injects. But the frequency of injecting is quite low in prisons so people entering prisons generally are injecting at about 100 times a month before they get into prison, as compared with the average rate of about 50 or 60 times a month; once they enter prison they’re injecting about 5 times a month. So many people draw encouragement from that and assume that that means low risk. But when you look at it more carefully what you see are two very disturbing features. One is that each episode of injecting in prison is far more hazardous than a corresponding injecting episode occurring outside prison. And this is partly because of large numbers of sharing partners and a very high rate of partner change. That means that a single injection in prison is far more likely to cause a hepatitis C infection than in the community...

200 Ms Alita O’Meara, public health nurse, CHS, Goulburn hearing, 8 May 2001.
201 NSW Hepatitis C Strategy at page 20.
204 Examples include: CHS, Submission No. 31; NSW Council of Social Service, Submission No. 76; HCC NSW, Submission No. 80; The Positive Justice Centre, Submission No. 78; NUAA, Submission No. 68; Individual Submission No. 45; and prison hearings, May and July 2001.
205 Dr Alex Wodak, Sydney hearing, 2 August 2001.
206 NUAA, Submission No. 68.
Evaluations of needle and syringe exchanges in European prisons are favourable. A Swiss evaluation of a prison-based syringe exchange program found that the frequency of drug use and injection remained stable and sharing had virtually ceased. There were no seroconversions to HIV, hepatitis B or hepatitis C during the study period.\(^{207}\) Fears that needles and syringes would be used as weapons have been raised as an issue of concern in relation to the provision of needles and syringes in NSW custodial settings.\(^{208}\) The evaluation of the Swiss Hindelbank project concluded:

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The results of the pilot project undertaken at Hindelbank institution do not provide any argument against the continuation of the distribution of sterile syringes. The fears expressed at the beginning — that drug use would increase and that needles would be used as weapons or accidentally cause injuries — were unjustified.\(^{209}\)
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The NSW Parliamentary Committee recommended that the NSW Ministerial Advisory Committee on Hepatitis investigate and report on the appropriateness of introducing a needle and syringe exchange program, modelled on the successful European trials, in the State's correctional system and, if necessary, develop guidelines for the program's implementation.\(^{210}\) The NSW Government’s response to the Parliamentary Committee’s report states that this recommendation is not supported.\(^{211}\)

### Access to bleach

Since 1992 the DCS’s policy is to make bleach freely available in all correctional centres for staff and inmate use.\(^{212}\) The bleach is used for cleaning injecting equipment. There are doubts, however, about the effectiveness of the recommended bleach cleansing of injecting equipment.

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Infection during injecting drug use is likely to be a leading mode of HCV transmission in prisoners. Inmates report that injecting apparatus is scarce in the prison system, whereas heroin is readily obtained. These circumstances favour repeated use of a limited number of needles and syringes by many prisoners. The recommended bleach cleansing of the injecting equipment appears ineffective, as our report corroborates previously documented transmission of HCV, but not HIV, after sharing of cleaned injecting apparatus.\(^{213}\)
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While there are concerns regarding the effectiveness of bleach cleansing of injecting equipment, the lack of needle and syringe programs in custodial settings makes the continued availability of bleach essential at this point in time.

The NSW Parliamentary Committee’s report states:

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…surveillance policies tend to induce a need for secrecy and speed to avoid detection and punishment. As a result the cleaning that does occur may not be effective in preventing the transmission of blood borne viruses such as Hepatitis C. The committee understands that bleach is not always readily available and there is some debate over the efficacy of bleach. Further, as Crofts has documented, some prisoners report that a request for bleach to disinfect injecting equipment is often followed the next day by a urine test.\(^{214}\)
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There have been two studies undertaken in relation to the bleach programs in NSW prisons which found that most inmates could obtain bleach and most were using it to clean injecting equipment.\(^{215}\) However, evidence to the Enquiry indicates that there remain some concerns about access to bleach in some prisons and whether surveillance of those who access bleach leads to reduced use of bleach to clean injecting equipment.\(^{216}\)

The Parliamentary Committee recommended that the Minister for Corrective Services ensures that adequate bleach-dispensing machines are available in all correctional centres enabling inmates to access bleach freely and anonymously. Bleach should be administered as a hepatitis C control measure and should not be linked to drug surveillance.\(^{217}\)

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\(^{208}\) Hepatitis C: The neglected epidemic, at page 372.


\(^{210}\) Hepatitis C: The neglected epidemic, at page 372.


\(^{214}\) Hepatitis C: The neglected epidemic at page 75.


\(^{216}\) Prison hearings, May and July 2001.

\(^{217}\) Hepatitis C: The neglected epidemic at page 353.
Access to drug treatment programs

Prisoners maintained on methadone inject half as often as those not in treatment, but only when daily doses reach 60 mgs and treatment is provided for the entire duration of incarceration.\[^{218}\]

The methadone maintenance program in correctional centres in NSW has been operating since 1986. Evidence to the Parliamentary Committee indicated strong support for and recognition of the prison methadone maintenance program. There was considerable evidence to the Parliamentary Committee that there was unmet demand for access to the methadone maintenance program. The CHS’s submission to this Enquiry states:

The methadone maintenance program operating since 1986 is the most comprehensive program in any correctional centre in the world — currently up to 1200 inmates receive methadone while in prison. This accounts for approximately 18 percent of the total number of methadone places in NSW. However it should be noted that even this situation addresses, at best, a half of the potential beneficiaries (given an estimated 40 percent of inmates being active heroin users at the time they join prison).\[^{219}\]

Safe tattooing

Tattooing is an illegal activity in NSW custodial settings. A NSW study found that prisoners estimated that 40% of fellow inmates had used tattoo needles and that 68% of these shared the tattooing equipment.\[^{220}\] A number of submissions to the Enquiry raised concerns about the risks associated with unauthorised tattooing in custodial settings in NSW.\[^{221}\]

The only strategy likely to reduce tattoo related hepatitis C transmission is to train inmates in infection control procedures and provide them with autoclaves and single use ampoules of ink. Penalties for tattooing in prison should be removed.\[^{222}\]

The Australian National Council on AIDS, Hepatitis C and Related Diseases has written to the Ministers for Corrective Services in each State and Territory urging them to permit and arrange for a system of safe tattooing within all in Australian correctional facilities as a significant means to combat the spread of HIV and hepatitis C infection.

Undifferentiated penalties for injecting drug use and cannabis

The fact that the same penalties apply whether a prisoner tests positive on urinalysis for cannabis or injectable drugs such as heroin has been raised in evidence to the Enquiry.\[^{223}\]

…the regulations tend to be pushing prisoners on to injecting drug use — the urine tests are far more effective with cannabis than anything else. The surveys we’ve done show...about 20% of the regular injecting drug users in prison started injecting drugs in prison…It’s actually driving people towards…risk-taking behaviour.\[^{224}\]

Differentiating punishment for the use of different drugs has been proposed.\[^{225}\]

Juvenile detention centres

The NSW Hepatitis C Strategy recognises young offenders as a priority group. The strategy notes that while there is some information regarding prevalence and incidence of hepatitis C in juvenile detention centres, measuring the incidence is difficult as testing is voluntary. The strategy recognises that early intervention strategies are important.\[^{226}\] Anecdotal evidence suggests that approximately one-third of young people entering Cobham Juvenile Justice Centre have used drugs intravenously and approximately two-thirds of those tested for hepatitis C are positive.\[^{227}\] The Department of Juvenile Justice in partnership with the CHS will be conducting a comprehensive health survey of its clients in early 2002. Planning for this survey has already commenced and should provide important data when completed.

\[^{219}\] CHS, Submission No. 31.
\[^{221}\] Health care worker, Lismore hearing, 23 May 2001.
\[^{223}\] HCC NSW, Submission No. 80.
\[^{224}\] Mr Michael Strutt, Sydney hearing, 3 August 2001.
\[^{226}\] NSW Hepatitis C Strategy at page 11.
\[^{227}\] Department of Juvenile Justice, Submission No. 109.
The Department of Juvenile Justice's submission to the Enquiry outlines intake procedures and hepatitis C services provided in juvenile detention facilities. These services include:

- comprehensive health assessment within 24 hours of admission to a Juvenile Justice Centre
- voluntary hepatitis C testing accompanied by pre and post test counselling
- brief interventions specific to hepatitis C and risk reduction
- health and lifestyle education and information for individuals and groups
- community links for ongoing support and treatment
- piloting of a youth-specific hepatitis C video in conjunction with the Centre for Research and Education on Drugs and Alcohol
- provision by local Area Health Services of outreach sexual health clinics in six of the nine detention centres.

The Department of Juvenile Justice's submission also outlines departmental policy and procedures, and training and education initiatives in relation to infection control and hepatitis C, including:

- funding for all registered nurses to receive specific training in HIV and hepatitis C pre and post test counselling
- induction training for senior youth workers on infection control procedures
- departmental infection control guidelines.

Diversionary schemes — Youth Drug Court Pilot

The Enquiry conducted a private hearing at the offices of the Joint Assessment Review Team, which is an internal part of the Youth Drug Court Program. The Youth Drug Court Program was established as part of the NSW Drug Summit 1999 Government Plan of Action. The Youth Drug Court is a new court set up to address the needs of young offenders who have drug and alcohol problems. The Youth Drug Court Program aims to divert young offenders from further drug use and reoffending by providing specialist assistance with their health, social, educational, offending and accommodation problems. The Youth Drug Court Program is a two-year pilot, which commenced operation in July 2000.

When a young person is convicted in the Children's Court they may be referred to the Youth Drug Court for initial assessment to determine their eligibility for the program. If eligible and the magistrate agrees, the young offender is comprehensively assessed by the Joint Assessment Review Team. The Joint Assessment Review Team comprises representatives from the Departments of Community Services, Juvenile Justice, Education and Training, and NSW Health. Once accepted onto the Youth Drug Court Program, a case plan is developed, and access to services and programs to meet the special needs of the young person are arranged and provided.

At the end of the six-month plan the young person appears before the Children's Court for an assessment of their Youth Drug Court Program attendance and progress, and for final sentencing. If the Youth Drug Court Program was followed, the Magistrate may choose not to sentence the young person to time in custody.

The range of services to which young people on the program have access include:

- welfare
- accommodation
- health
- training and education
- rehabilitation and detoxification
- living skills
- counselling.

Young people within the juvenile justice system are likely to experience the greatest difficulties in accessing testing, health promotion and health care services. The assessment process involved in the Youth Drug Court Program provides an important opportunity to ensure that the most marginalised young people with hepatitis C and those most at risk of infection have access to hepatitis C testing, health care services, health promotion and prevention education.

The program has been the subject of an initial evaluation report and will be formally evaluated in order to consider its effectiveness. The Enquiry considers that diversionary programs such as the Youth Drug Court Program, which take a holistic approach and address the causes of drug use, are a vital part of increasing the
most marginalised young people’s access to health and related services. It is essential that the opportunities for ensuring young injecting drug users have access to drug and alcohol treatment services, hepatitis C testing, health care, health promotion and hepatitis C prevention are not limited to the worst case scenario — when young people are incarcerated in juvenile detention centres. The Enquiry supports the *NSW Hepatitis C Strategy*’s stated commitment to increasing such diversionary schemes.229

**Coverage under federal and NSW anti-discrimination law**

Generally, federal and NSW anti-discrimination legislation provides that it is unlawful to discriminate against a person on the basis of their hepatitis C status, in specific areas of public life, including the provisions of goods and services. Where the evidence to the Enquiry raises specific instances of discrimination on the basis of a person’s hepatitis C status, anti-discrimination legislation may apply.

Generally, both the ADA and DDA provide that it is unlawful to discriminate against a person with hepatitis C, in the provision of goods and services, both by refusing to provide the service or in the terms on which the service is provided.230 Whether or not the DCS and the Department of Juvenile Justice are considered to be providing a service to people in custody within the meaning of the ADA, will depend upon the nature of the discrimination alleged. However, a number of cases have found that correctional authorities do provide services to prisoners in their custody and care.231 In the case of *X & Anor v The State of Western Australia*, two HIV-positive prisoners were awarded $8,000 and $3,000 respectively by way of compensation after HREOC found their complaints of discrimination on the basis of their HIV status to be substantiated. The prisoners had been segregated from the mainstream prison community and been denied the opportunity to be involved in work, sporting, recreational and other activities available to mainstream prisoners because of the existence of a policy which was found to be profoundly discriminatory against HIV-positive prisoners. In reaching this conclusion, HREOC found that the respondent was providing ‘services’ within the meaning of section 4 of the DDA.232

This issue was also considered in the Western Australian case, *Hoddy v Executive Director Department of Corrective Services*. An HIV-positive prisoner alleged he was denied access to certain activities which were available to minimum security prisoners including various work arrangements, educational classes and health promotion programs on the basis of his HIV status.233 The WA Equal Opportunity Tribunal found that it was open to the complainant to complain of discrimination in regard to the provision of services or the availability of facilities because the respondent did provide services to prisoners in their custody and care.

**Policy context**

The Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) has commissioned the development of best practice guidelines for correctional settings, in relation to prevention of HIV/AIDS and hepatitis C, and models of care for people living with HIV and hepatitis C. These guidelines are currently being developed and may provide useful guidance for future policy and service delivery reform in NSW. It is anticipated that the guidelines will be finalised by early 2002.

The *NSW Hepatitis C Strategy* outlines a range of key initiatives in relation to hepatitis C clinical services and prevention generally, and in relation to correctional settings specifically, including:

- increasing the provision of methadone maintenance treatment
- examining the possibility of differential sanctions for drug possession and drug use in correctional centres
- suitable education regarding hepatitis C upon entry to prison
- access to liver biopsy at locations in addition to Long Bay hospital
- improved continuity of care of inmates, post release.

The Enquiry strongly supports the commitments outlined in the Strategy.

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229 *NSW Hepatitis C Strategy* at page 19.
230 ADA, section 49M; DDA, section 24.
233 *Hoddy v Executive Director Department of Corrective Services* (1992) EOC 92-397.
Conclusions and recommendations

People in custodial settings should have access to health care services and programs of a standard equivalent to that available in the community. While evidence to the Enquiry indicates that discrimination on the basis of inmates’ hepatitis C status does occur, the most pressing concerns raised are in relation to access to health care, health promotion and hepatitis C prevention programs and services for prisoners, regardless of whether they have hepatitis C. Impediments to the effective delivery of health care and health promotion services in custodial settings have significant and detrimental consequences for the health of all prisoners, including many hepatitis C positive inmates in the NSW correctional system. Consideration is therefore given to policy recommendations which aim to address these concerns.

Issues relating to hepatitis C prevention in NSW custodial settings have been examined and recommendations made in a number of key reports in recent years. Many submissions to the Enquiry raised ongoing concerns about the inadequacies of current hepatitis C prevention strategies in custodial settings. The Enquiry concludes that there remains a pressing need to address the unacceptably high risk of infection with hepatitis C within the correctional system. Recommendations and/or proposals for reform to reduce hepatitis C transmission in the NSW correctional system have been considered in detail by the NSW Parliamentary Committee’s report, among others. The Enquiry endorses the recommendations outlined below which it considers are critical to reducing hepatitis C transmission in the correctional system.

Access to health care

The Enquiry recommends that:

31. NSW Health recognise the importance of the integration of health promotion and hepatitis C prevention within the clinical service delivery provided by the CHS, and ensure that the health promotion and hepatitis C prevention services provided by the CHS are adequately funded.

32. NSW Health ensure adequate resources are provided for the capacity building necessary to enable the effective implementation of the CHS hepatitis C continuum of care, including implementation of specific protocols incorporating health promotion, prevention, services for newly diagnosed inmates, ongoing clinical management and discharge planning.

33. The DCS and the CHS develop and implement protocols to enable effective discharge planning to maximise prisoners’ access to health services post release.

34. NSW Health, in conjunction with the CHS, other relevant Area Health Services and the DCS, develop service protocols to improve prisoners’ access to hospitals for day-only procedures and agreed mechanisms for linking prisoners into health services in the community, post release.

35. The NSW Ministerial Advisory Committee on Hepatitis give consideration to the emerging scientific literature that indicates that liver biopsy may not be mandatory in order to determine whether treatment is indicated and, if appropriate, enable the use of serological markers to assess liver damage, in order to maximise inmates’ access to hepatitis C treatment.

36. The DCS provide the NSW Ministerial Advisory Committee on Hepatitis with the report arising from the review of the Alcohol and Other Drugs and HIV Health Promotion Units and updated information as requested by the Committee to enable the Committee to examine whether the health promotion and hepatitis C prevention education services and programs provided by the DCS are adequate to meet demand.

37. The DCS evaluate the currency of information in the HIV/AIDS communicable diseases and health promotion policies and procedures, particularly the coverage of hepatitis C, and the extent to which these policies and procedures reflect current practice.

38. The DCS update the HIV/AIDS communicable diseases and health promotion policies and procedures, in line with the review and evaluation findings.

39. The DCS ensure the effective implementation of revised policies and procedures, with particular emphasis on education and training in relation to standard infection control procedures and a systematic approach across the correctional system to the provision of information and education to inmates about hepatitis C prevention and health promotion.
Hepatitis C prevention

The Enquiry endorses the following recommendations and/or proposals for policy or service reform considered above:

40. The NSW Ministerial Advisory Committee on Hepatitis investigate and report on the appropriateness of introducing a needle and syringe exchange program, modelled on the successful European trials, into the State’s correctional system and, if necessary, develop guidelines for the program’s implementation.

41. The Minister for Corrective Services ensure that adequate bleach dispensing machines are available in all correctional centres enabling inmates to access bleach freely and anonymously. Bleach programs should be administered as a hepatitis C control measure and should not be linked to drug surveillance.

42. NSW Health ensure that the CHS has adequate resources to meet the treatment needs of opioid dependent inmates, particularly to ensure access to methadone, and other therapeutic options such as naltrexone and buprenorphine.

43. The Minister for Corrective Services enable tattooing to be available in hygienic conditions within the NSW correctional system. Consideration should be given to:
   - trialing the availability of professional tattooists in the correctional system
   - training inmates in the infection control procedures necessary for safe tattooing and supplying inmates with single use ampoules of ink and autoclaves.

44. The Minister for Corrective Services give consideration to differentiating between the punishment for the use of cannabis and injectable drugs in custodial settings.

45. The NSW Government increase the range of non-custodial and diversionary programs to reduce incarceration.

2.6 Insurance

Overview

The evidence to the Enquiry indicates that people with hepatitis C are routinely refused insurance or dissuaded from applying for insurance because of their hepatitis C status. The majority of submissions relate to life insurance, although there is also evidence that this occurs in relation to applications for income protection, sometimes called disability income insurance. The income protection is also commonly a type of life insurance. Where applications are made by people with hepatitis C, it appears common for such applications to be refused without regard to medical evidence about individual prognoses. The evidence also raises concerns regarding reliance upon actuarial evidence which is either out of date or based on data which is not relevant to the Australian context.

Reliance upon actuarial data as a basis for refusal of insurance coverage is relevant to specific exceptions under both federal and NSW anti-discrimination laws, which are considered below.

In its submission to the Enquiry, the Hepatitis C Council of NSW states:

‘…their decision was based on one result and ignoring all the other information including my specialist’s report and general practitioner’s physical examination that both indicated and stated I was in excellent health.’ Bob wanted the insurance company to ‘change its policy to cover individual circumstances rather than taking a blanket view regarding people with HCV.’

234 HCC NSW, Submission No. 80.
Unnecessary hardship has been created by continued use of outdated actuarial information among life assurance companies and underwriters — often leading to exclusion of potential policy holders with hepatitis C.

I disclosed my viral status on the form, and was refused insurance. I felt angry because the response seemed to be a knee-jerk one, and I didn’t feel that it was based on a realistic understanding of…people with hep C. Many of us are not necessarily all that high a risk for insurance companies…Isn’t that what insurance companies are supposed to do — take calculated risks? It seems to me that they are unwilling to take any risks at all.

The provision of insurance is a commercial activity and fundamental to the process of insuring a person against future illness, injury or death, is the need to assess the particular risk factors for injury, illness or early death. Such an assessment of risk may lead to differential treatment based on the degree of risk associated with providing insurance to one person compared with another. This may mean that an individual with hepatitis C is assessed as a higher risk for making a claim based on medical evidence about their prognosis, among other factors. This may mean they are required to pay a higher premium than a person who does not have hepatitis C. However, the current evidence about the natural history of the virus clearly indicates that routine refusal of insurance and exclusion of people with hepatitis C from applying for insurance as a matter of standard policy are not justified.

HREOC has produced guidelines to support insurers compliance with their obligations under the DDA. These guidelines provide that:

- insurers should use information about the person seeking insurance, such as a person’s medical records
- underwriting manuals should be based on relevant actuarial or statistical data or medical opinion and updated as necessary to take into account the latest advances in medicine relevant to the particular disability.

Relevance of natural history of hepatitis C

Hepatitis C is a slow-acting virus, and for the majority of people infection will not result in serious disease or death. A review of studies on the natural history of approximately 25% of people with hepatitis C infection will clear the virus spontaneously within two to six months of infection, of the remaining 75% of people, only a small proportion will develop cirrhosis of the liver. The natural history of hepatitis C is considered in detail in Chapter 1.

Dr Greg Dore’s evidence to the Enquiry indicates that the evidence in relation to both the natural history of hepatitis C and the impact of anti-viral therapy in recent years has significantly improved the outlook for people with hepatitis C.

The reality is that the vast majority of people living with HCV will not die as a direct consequence of that viral infection. We know that a proportion of people will progress to advanced liver disease but this proportion is considerably lower than it was initially envisaged….We have also had great advances in treatment of HCV and we are now starting to use the word ‘cure’ in relation to HCV treatment. Probably 40%–50% of people

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235 AHC, Submission No. 60.
236 Individual Submission No. 42.
237 Individual Submission No. 27.
238 Individual Submission No. 13.
who go on to anti-viral therapy are able to be cured of HCV. If we put together the improving knowledge of the underlying natural history with the advances in treatment, the outlook for people living with HCV is much more optimistic than it was several years ago.241

Evidence to the Enquiry indicates that even the distinction between a person who has tested positive to the presence of antibodies, but does not in fact have the virus, compared with a person who has the virus is often misunderstood.

...individuals are ‘penalised’ [in relation to insurance] by their hepatitis C antibody status, irrespective of whether they have liver disease or not (PCR negative are treated the same as PCR positive).242 [sic]

If the PCR tests come back negative the risk of transmission is basically zero and they are not going to progress to advanced liver disease. That has an enormous role in reducing anxiety. Whether it has any role in reducing discrimination I don’t know...in the area of life insurance I’d like to see that it does because people’s life expectancy is normal if they don’t have active infection.243

People who have tested antibody positive, but HCV RNA (PCR) negative are not at risk of the symptoms associated with the hepatitis C virus, unless they are subsequently reinfected. Accordingly, there is no justification for refusing to insure people on the basis of their hepatitis C antibody status. Current literature on the natural history of hepatitis infection estimates that of the remaining 75% of people with hepatitis C virus, only 5–10% will progress to cirrhosis by 20 years and possibly 20% by 40 years infection.244

Risk assessment

The process of risk classification is commonly known as underwriting. Reinsurers’ underwriting manuals are prepared for insurance companies on the basis of available research data relating to the natural history of a particular condition and statistical evidence in relation to other co-factors which may increase the likelihood of a claim, in order to determine the level of risk associated with insuring people who have hepatitis C on a population basis. Each life insurance company has underwriting guidelines or manuals which cover many medical conditions. These are commonly based on reinsurers’ underwriting manuals. These underwriting manuals provide the basis for insurance companies’ decisions about whether to insure a person with a particular condition and, if so, what premiums should be payable. Premiums are then determined according to the risk associated with insuring the particular person.

In light of the current natural history research, insurers should consider each application for life insurance on an individual basis. A person’s application for insurance should be assessed in light of relevant medical evidence regarding their individual prognosis and any other co-factors which may indicate the likelihood that the person may make a claim. There are a range of indicators which may influence disease progression that can be considered when insurance companies are assessing the likelihood that a claim may be made as a result of the person’s hepatitis C status. For example, progression to liver cirrhosis is more likely among people with a heavy alcohol intake, co-infected with HIV or chronic hepatitis B infection, and those with severe liver scarring. Liver function tests are commonly used as a means of monitoring the condition of the liver and liver biopsies can determine the degree of liver damage, if any. Several factors affect response to treatment including the person’s age, duration of infection and gender, but by far the most important factor is the particular strain of the virus that the person has. In Australia there are three main genotypes: 1, 2 and 3. Dr Greg Dore outlined the effectiveness of treatments for each genotype as follows:

Genotype 1 responds quite poorly to anti-viral therapy (about 20%–25% of people with genotype 1 reach sustained response after the standard treatment of interferon and ribavirin). If you have Genotype 2 or 3 the sustained response rate is in the order of 70%.

Genotype 1 makes up about 45–50% of Australian HCV genotypes, 2 is about 15% and 3 is about 35% then you have 5% of other genotypes. Genotype 4 is predominantly among Egyptians and the prevalence there is quite high, and genotypes 5 and 6 are predominantly from South East Asian communities where the prevalence is also high.245

Natural history varies according to these particular co-factors. As a result, it is important that insurance companies rely on actuarial or statistical evidence that is specifically relevant to the Australian population of

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241 Dr Greg Dore, NCHECR, Sydney hearing, 3 August 2001.
242 Central Sydney AHS, Submission No. 19.
244 Dore, G. Natural history of hepatitis C virus infection at page 7.
245 Dr Greg Dore, Sydney hearing, 3 August 2001.
people with hepatitis C. For example, HIV is a co-factor for disease progression. So a person who has HIV and hepatitis C has a significantly higher risk of progressing to advanced liver disease. In Australia co-infection is very low and only 1% or lower of our total population of people with hepatitis C have HIV co-infection. In countries like Spain, Italy and parts of the USA where the prevalence of co-infection is quite high, advanced disease outcomes are more prevalent than in Australia.246

The Investment and Financial Service Association (IFSA) presented useful and significant evidence to the Enquiry which supports the view that there is no justification for life insurance companies to routinely refuse insurance to all people with hepatitis C.247 IFSA’s evidence to the Enquiry indicates that:

- people with hepatitis C are insurable in the majority of cases
- the main factors taken into account in determining the level of risk associated with insuring a person with hepatitis C are the person’s age, liver function and alcohol intake
- risk assessments are based upon extensive, relevant and reliable data.248

This evidence suggests a far more encouraging outlook for assessment of applications for life insurance by people with hepatitis C in the future. Nonetheless, it is clear that the evidence to the Enquiry indicates that such an approach is not necessarily reflected in the policies and practices of life insurance companies to date. It is also important to understand IFSA’s role. IFSA is a professional association, whose members are life insurance companies. Approximately 95% of all life insurance companies currently active in the marketplace are members of IFSA.249 The above position outlined by IFSA in their evidence to the Enquiry is not a policy position with which members are required to comply. Rather, as outlined earlier, each insurance company has its own underwriting guidelines, based on underwriting manuals provided by reinsurers. The insurance company then assesses the information in the underwriting manual and determines its own policies and premiums.

**Coverage under federal and NSW anti-discrimination law**

The Deputy Disability Discrimination Commissioner, Mr Graham Innes, explains the obligations of insurers in respect of disability discrimination under the DDA, which also reflects insurers’ obligations under the ADA, as follows:

The legislation recognises that the nature of insurance is one of making differentiations based on risk — at least, that is the case outside of the health insurance area where the community rating principle applies. Even there, exclusions on payment for pre-existing conditions recognise that insurers are in the business of insuring against risks, not already known certainties. Of course, insurers are no more entitled than any other industry to act on basis of prejudices, misconceptions or inaccurate or outdated information about people with disabilities. But the Disability Discrimination Act does permit distinctions and exclusions based on disability if and where this is reasonable.250

Generally, under both NSW and Commonwealth anti-discrimination legislation, insurance providers cannot discriminate on the ground of disability, including hepatitis C, by refusing to provide insurance or by offering unfavourable terms or conditions to a person with hepatitis C.

The ADA provides that it is unlawful to discriminate against a person with hepatitis C, in the provisions of goods and services, both by refusing to provide the service or in the terms on which the service is provided.251 The provision of insurance is considered a service within the meaning of the ADA.252 However, the ADA does not apply to life insurance, which also includes insurance for continuing disability. For constitutional reasons, because the Commonwealth has specifically legislated in relation to life insurance, the ADA does not apply, but complaints in relation to discrimination in the provision of insurance can be made under the Commonwealth DDA.253 Other types of insurance are covered by the ADA, although there is an exception

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246 Dr Greg Dore, Sydney hearing, 3 August 2001.
247 Mr Michael Molesworth, GeneralCologne Life Re Australia on behalf of IFSA, Sydney hearing, 3 August 2001.
248 IFSA, Submission No. 110.
249 Personal communication with Mr David Mico, Senior Policy Manager, IFSA, 6 August 2001.
251 ADA, sections 49B and 49M.
252 ADA, section 4.
in relation to insurance. In order to rely upon this exception, the insurer needs to be able to demonstrate that it is reasonable to discriminate against the person given the available actuarial or statistical data, or where such evidence cannot reasonably be obtained, that the terms and conditions are reasonable having regard to any other relevant factors.254

The DDA provides that it is unlawful to discriminate against a person with a disability, in the provisions of goods, services and facilities, including refusing to provide a service and in the terms on which the service is provided.255 The provision of insurance is considered a service within the meaning of the DDA. 256 The DDA also provides an exception in relation to insurance, in similar terms to the insurance exception provided in the ADA.257

Although many of the circumstances outlined in evidence to this Enquiry generally may be covered by anti-discrimination law, few complaints are lodged. Overwhelmingly, the burden of enforcing anti-discrimination law lies with the individual. This is considered in detail in Chapter 4. This presents particular challenges in the context of alleged discrimination by the insurance industry. Where an application for insurance is refused, the onus is on the individual to lodge a complaint under anti-discrimination law, bringing with it the prospect of the slow, expensive and stressful processes of investigation, conciliation, and possibly litigation, against an insurer with considerable greater financial resources than most individuals.

**Policy context**

As discussed above, the ADA does not apply to life insurance and as such the ADB does not have jurisdiction to consider such complaints. However, complaints of hepatitis C discrimination in the provision of life insurance can be made under the DDA. As such, HREOC is well placed to pursue policy solutions to hepatitis C related discrimination in the provision of life insurance.

HREOC has recently announced draft terms of reference for a proposed inquiry: Insurance discrimination, depression and anxiety disorders. Given that this Inquiry will examine disability discrimination issues in the context of the provision of insurance, and through this will be working with key insurance industry bodies, an opportunity exists to pursue the issues raised by the evidence to this Enquiry. The Enquiry considers that it would be of considerable benefit to examine disability discrimination and insurance more broadly, rather than limit the Inquiry to depression and anxiety disorders in particular.

**Conclusions and recommendations**

The evidence to the Enquiry indicates:

- that people with hepatitis C are being routinely refused insurance or dissuaded from applying for insurance
- that it is common for applications for insurance to be refused without regard to medical evidence about people’s individual prognoses
- such policies and/or practices are inconsistent with current natural history research and clinical evidence about hepatitis C disease progression.

The Enquiry recommends that:

46. HREOC’s proposed public inquiry into insurance discrimination, depression and anxiety disorders be expanded to an inquiry into disability discrimination and insurance to enable hepatitis C related discrimination to be considered.

47. HREOC encourage the participation of key community and industry stakeholders and research bodies including the Investment and Finance Services Association, the Institute of Actuaries of Australia, the Australian Hepatitis Council, the Australian Intravenous League and the National Centre in HIV Epidemiology and Clinical Research.

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254 ADA, section 49Q.
255 DDA, sections 5 and 24.
256 DDA, section 4.
257 DDA, section 46.
2.7 Funeral industry services and autopsy procedures

Funeral services

The funeral directors made a phone call to my family stating in the call…‘the bad news is that your son had hepatitis C and it is a highly contagious disease. Because you’re not allowed to view a person with hepatitis C there can’t be a viewing’. It wasn’t until months later when I found that we as a family had every right to view my brother.258

The undertaker said, ‘he’s got to be in a plastic bag’. And I said, ‘sorry, that’s not going to happen’, and I stood my ground and I actually picked my husband up from the mortuary where I gave them clothes to dress him in…259

Evidence to the Enquiry indicates that where deceased persons are known or assumed to be hepatitis C positive, family and friends are routinely denied the right to view the body. Submissions from the Hepatitis C Council of NSW and the Hepatitis C Council of South Australia indicate that this type of discrimination in the funeral industry is commonplace and has devastating consequences for people during a very stressful time in their lives.260

One of the biggest complaints, and this came to me from the Koori community…is undertakers…I can’t for the life of me see why if you can live with somebody and sleep with somebody and they die then suddenly you can’t say goodbye to them…I don’t know whether they even know if the people are HCV+[…it’s enough] if they have been injecting drugs.261

One thing that is really concerning me now is this issue about when I die, like is this HCV [discrimination] going to continue…when my family, my two kids and my wife are not allowed to see me…that’s really affecting me.262

Evidence provided to the Enquiry indicates undertakers commonly cite public health law as the basis for refusing to allow family and friends to view the body. It appears that funeral industry staff are basing such decisions on incorrect assumptions about hepatitis C transmission, even though refusing family and friends the opportunity to view the body of deceased persons with hepatitis C or assumed to have hepatitis C is inconsistent with the provisions of the Public Health Regulations 1991 (NSW).

The Public Health Regulations provide that hepatitis C is classified as a ‘List A’ condition.263 An undertaker may remove a body, which the undertaker has reason to believe is infected with a List A disease, from a body bag for the purpose of preparing the body for viewing, transport, burial or cremation.264 The regulations also specifically provide that an undertaker may make available for viewing by mourners a body which the undertaker has no reason to believe is infected with a ‘List B’ disease.265 As hepatitis C is a List A condition, there is no prohibition on the viewing of a deceased person with hepatitis C. Clause 29(3) of the regulations does, however, provide that an undertaker can refuse to make available for viewing or terminate the viewing of a body if the undertaker has reason to believe that the viewing will be, or will become, prejudicial to public health or amenity. However, as hepatitis C is a blood-borne virus, there is generally no reason to believe that viewing the body of a deceased person with hepatitis C poses any threat to public health, either in relation to the person viewing the body or the employees of the funeral industry in preparing the body for viewing. Failure to comply with the Public Health Regulations amounts to an offence under the Public Health Act 1991 (NSW).266 This position is confirmed by a recent published correspondence from a forensic technician employed by the Westmead Coronial Morgue, which states:

Here at the Westmead Coronial Morgue, Sydney, we advise families on the funeral industry’s general viewing restrictions [under PHR] in order to prevent confusion. This is especially so in the case of deceased persons

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258Individual Submission No. 10.
260HCC (South Australia), Submission No. 75; HCC NSW, Submission No. 80.
263PHR, clause 18.
264PHR, clause 28(2).
265PHR, clause 29(1).
266PHA, section 82.
with suspected or known hepatitis C infections (e.g. accidental injecting drug overdose). There is no valid reason why funeral directors should refuse the viewing of a deceased person with hepatitis C.267

Evidence indicates that people are often unaware of their rights in relation to viewing the body of a deceased person. In addition, when such circumstances arise, people are often at their most vulnerable and, as a result, are unable to challenge the assertion that viewing the body of a person with hepatitis C or assumed to have hepatitis C is contrary to public health law at the time of the refusal. This means that family and friends are denied the opportunity to view the body, even where they do take action to raise their concerns subsequently.

Funeral directors pulled the wool over our eyes, said ‘no you can’t view the body’, they’re thinking the family is not going to do research on it and they’ll get away with it and how many times do they get away with it, they get their costs at the end of the day and they don’t understand the emotions that family or the loved one has to then deal with.268

**Legislative remedies**

**Public Health Act 1991 (NSW)**

When a person alleges they have been unlawfully denied the opportunity to view a deceased person because the deceased is assumed to be or is infected with hepatitis C, this is a matter for NSW Health. NSW Health has the capacity to investigate any alleged breaches of the *Public Health Regulations* and, where necessary, to prosecute such breaches in the Local Court.

**Anti-Discrimination Act 1977 (NSW)**

A complaint under the ADA about the refusal by funeral services to allow family or friends the right to view the body of a deceased person with hepatitis C is unlikely to succeed as a complaint of discrimination, as such circumstances are not currently covered by the ADA. The reason this is the case turns on the definitions of ‘relative’ and ‘associate’ under the ADA.

As previously outlined, it is generally unlawful to discriminate against a person with hepatitis C in the provision of goods and services. The ADA also enables a person to lodge a complaint under the Act where a person has been discriminated against on the basis of the disability of a relative or associate. However, the definitions of ‘relative’ and ‘associate’ in the ADA refer to ‘a person’.

Section 4(1) provides:

- relative of a person means any person to whom the person is related by blood, marriage, affinity or adoption.
- associate of a person means:
  a) any person with whom the person associates, whether socially or in business or commerce, or otherwise, and
  b) any person who is wholly or mainly dependent on, or a member of the household of, the person.

As a result, the relative or associate of the would be complainant, in circumstances where viewing of a deceased person is refused, is not legally a ‘person’, as they are deceased. Similar difficulties arise under the DDA, as the definition of relative and associate also refer to ‘a person’.269 This is an issue which requires legislative reform, to enable complaints to be lodged where the relative or associate with hepatitis C is now deceased.

**Law and policy reform**

In considering appropriate legislative and policy recommendations to address the issues raised regarding the viewing of deceased persons with hepatitis C or assumed to have hepatitis C, the Enquiry is conscious that NSW Health is currently undertaking a review of the *Public Health Act 1991* (NSW) and the *Public Health Regulations 1991* (NSW). In 1999 NSW Health released an Issues Paper to enable participation in the review. Infection control in relation to requirements surrounding the preparation and transportation of deceased persons was considered.270 NSW Health has engaged an independent consultant to prepare a report on the options for regulation of the funeral industry.271

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269 DDA, section 4.
Given that evidence provided to the Enquiry indicates that undertakers commonly cite public health law as the basis for refusing to allow family and friends to view the body, despite provisions in the Public Health Regulations which provide otherwise, it is critical that the relevant provisions in relation to funeral industry handling of bodies are retained. Further, the Enquiry considers that there is a compelling case for the development of clear guidelines in relation to infection control in the funeral industry, particularly in relation to the handling of bodies, to support compliance with the Public Health Act and Regulations. As previously mentioned, recommendations have been made to the NSW Government about proposed amendments to the Public Health Act and Regulations.

The Enquiry is also aware that considerable work has already occurred in relation to the development of a Code of Practice on infection control for NSW funeral industry workplaces. The purpose of the Code is to assist employers and employees to meet their duty of care under OH&S legislation. The draft Code includes information on transmission risks associated with blood-borne viruses such as hepatitis C, guidelines for risk assessment and risk control, standards for training staff, and mechanisms for monitoring implementation of the Code.

The development of the Code is an initiative of the Funeral Industry Council, which includes representatives of funeral industry employees, the Funeral and Allied Industries’ Union of NSW, NSW Health, Department of Fair Trading, local government and consumer representatives. Unfortunately, the process for finalising the Code has been in abeyance since late 1998. Given this lapse of time, it appears unlikely that the work to date can form the basis of a new Code and work would need to commence afresh to work towards the development of a Code.

Generally, industry codes of practice under Occupational Health and Safety Act 2000 NSW (OH&S Act) can be approved by the Minister for Industrial Relations. The approval of such codes is then published in the NSW Government Gazette. Once gazetted, an approved code of practice is designed to be used in conjunction with OH&S legislation. A person or company cannot be prosecuted for failure to comply with an approved industry code of practice. However, in proceedings under the OH&S Act or Regulations, failure to observe the code can be used as evidence that a person or company has failed to comply with the OH&S Act or Regulations.

The Enquiry is of the view that a Code of Practice on infection control for NSW funeral industry workplaces would be of considerable benefit in ensuring compliance with OH&S, as well as providing a valuable resource for educating employers and employees in the funeral industry about hepatitis C transmission and the application of appropriate infection control measures.

Conclusions and recommendations

The evidence to the Enquiry indicates that:

- family and friends of deceased persons known or assumed to be hepatitis C positive, are routinely denied the right to view the body
- the rationale for refusal on public health grounds, cited by the funeral industry, is inconsistent with the Public Health Act 1991 (NSW) and Public Health Regulations 1991 (NSW).

The Enquiry recommends that:

48. In the context of any proposed changes to the Public Health Act 1991 (NSW) and Public Health Regulations 1991 (NSW), that specific reference to funeral industry practices in relation to the handling of bodies should be retained in the Public Health Regulations.

49. NSW Health, in conjunction with relevant government departments, industry bodies and consumer representation, develop and implement guidelines in relation to the funeral industry, including in relation to the handling of bodies, to ensure compliance with the Public Health Act 1991 (NSW) and Public Health Regulations 1991 (NSW), or such other public health legislation as may be enacted.

50. The WorkCover Authority of NSW, in conjunction with relevant government departments, industry bodies and community representation, develop a Code of Practice on infection control for NSW funeral industry workplaces pursuant to OH&S legislation.

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272 Code of Practice on infection control for NSW funeral industry workplaces, draft only, November 1998.
51. The WorkCover Authority of NSW, in conjunction with relevant government departments, work with industry bodies and relevant community agencies to ensure appropriate education and workforce development within the funeral industry to enable effective implementation of the Code of Practice on infection control for NSW funeral industry workplaces.

52. The NSW Government amend the definitions of ‘relative’ and ‘associate’ in the ADA to provide coverage where a person alleges they have been discriminated against on the basis of the disability of a relative or associate who is deceased.

Autopsies

The HIV/AIDS Legal Centre (NSW) has provided evidence to the Enquiry regarding the practice of a particular facility in relation to the reconstruction of the bodies of people with HIV after autopsy.

The main provider of autopsy procedures in New South Wales is the [Glebe] Institute of Forensic Medicine (the Institute). The current practice at the Institute is to refuse to reconstruct the bodies of HIV positive people after an autopsy. This has the consequence of preventing the families of positive people from viewing the bodies of the deceased if an autopsy has been performed. The Institute alleges that the risk of needle stick injury to workers suturing a body that is HIV positive is unacceptably high given that there is no therapeutic benefit to be gained from the suturing.274

The HIV/AIDS Legal Centre's submission states that they understand from discussions with the Institute that the Institute has a written policy on the reconstruction of bodies, but they are not willing to release that policy. The HIV/AIDS Legal Centre is of the view that such a policy or practice is not uniform across providers of autopsy procedures in NSW, citing the Westmead Coronial Morgue as a facility which does not follow this practice. They also state that this is not a policy or practice followed in other Australian States.

It is unclear from the HIV/AIDS Legal Centre's submission whether this practice applies to the reconstruction of the bodies of deceased persons with hepatitis C, although a recent correspondence published in the Hep C Review suggests that the practice does apply to hepatitis C.

The Glebe Coronial Morgue [has] the policy of not allowing the viewing of hepatitis C infected bodies after completion of an autopsy as they do not perform reconstruction of the deceased. This would hinder any request to Funeral Directors for a viewing, as the viewing of a body not yet reconstructed could be deemed possibly prejudicial to public health. The Glebe Morgue policy is directly related to the primary prevention of needlestick injuries to forensic technicians during reconstruction. But their use of personal protective equipment and use of forceps to hold tissue during suturing should eliminate needlestick injuries occurring. Currently at the Glebe Morgue, families requesting viewing should organise it prior to the autopsy examination being performed. In comparison, there are no viewing restrictions for deceased with hepatitis C at the Westmead Coronial Morgue and viewing in the morgue is offered to families where they have indicated such wishes.275

The risk of transmission of hepatitis C in health care settings is low.276 Dr Greg Dore, in his evidence to the Enquiry, stated:

There is about 5% risk of transmission through a needle stick injury with a patient who has chronic HCV. We have a National Occupational Exposure Network that reports incidents of occupational exposure. Many of these cases are reported but we have seen very few cases of HCV transmission despite having a base line rate of HCV, among the patients from which the injuries relate to, of 4–5%.277

Despite the risk of transmission, policies in other jurisdictions provide for reconstruction of bodies as a standard procedure. For example the Victorian Institute of Forensic Medicine's guidelines provide that hazardous autopsies are performed in the same manner as routine autopsy examinations, including the full reconstruction of the body.278 New Zealand mortuary guidelines also reflect this approach.279

While there are risks associated with reconstruction of the bodies of persons with hepatitis C, such risks can be significantly reduced by the application of infection control procedures. The rationale for a policy of non-reconstruction of bodies is that there is no therapeutic benefits to the deceased. This fails to acknowledge that

274 HIV/AIDS Legal Centre Inc (NSW), Submission No. 108.
277 Dr Greg Dore, Sydney hearing, 3 August 2001.
278 Mortuary autopsy work instructions, Victorian Institute of Forensic Medicine, Version 1, last authorised on 14 July 2000, at page 11.
279 Managing health and safety risks in New Zealand mortuaries, Department of Labour, Wellington, New Zealand, December 2000.
the viewing of a person's body can have great significance for family and friends of the deceased as part of their grieving process.

The Enquiry notes that the failure to reconstruct the bodies of deceased persons with HIV or hepatitis C may not necessarily prevent family and friends from viewing the body, as arrangements may be made for viewing to occur prior to the autopsy. As a matter of policy, every effort should be made to enable family and friends to view the deceased person prior to autopsy. This would substantially reduce the need for reconstruction of bodies after an autopsy. Where family or friends have not been provided with the opportunity to view the body and wish to do so, reconstruction of bodies should take place to enable viewing.

Policy Context

In March 2001 the Minister for Health, Mr Craig Knowles, established an Inquiry into the post-mortem and anatomical examination practices of the Institute of Forensic Medicine after allegations that staff at the Institute had behaved illegally in their handling of bodies and body parts following autopsy. Brett Walker SC conducted the Inquiry and his report was released in August 2001 (The Walker report). The Walker report does not have a direct bearing on the issues raised in this Enquiry as the Inquiry considered post-mortem examinations at the Institute of Forensic Medicine specifically in relation to the removal of body tissues and organs and did not consider procedures for reconstruction of bodies. However, as a result of the Inquiry findings, the Minister for Health for Health has announced that the Institute for Forensic Medicine at Glebe will be dissolved. The work of the Institute of Forensic Medicine is to continue as a section of the Division of Laboratory Medicine of the Central Sydney Area Health Service. Its work, and that of equivalent organisations based at Westmead and Newcastle, will be overseen and coordinated by a new state-wide statutory authority – the Forensic Medicine and Pathology Authority. Accordingly, the Enquiry’s recommendations in relation to reconstruction of bodies after autopsy are directed to NSW Health, Central Sydney Area Health Service and the proposed Forensic Medicine and Pathology Authority.

NSW Health’s current Infection Control Policy does not cover infection control in relation to post mortem care. However, this policy is currently under review. The current draft now provides some guidance in relation to post mortem care. It is of concern that the draft states that:

…under special circumstances non-restoration of bodies may be appropriate. If a body is not restored then all attempts should be made to enable viewing prior to autopsy.

The draft policy does not provide any information about what would constitute ‘special circumstances’, nor any rationale for adopting this approach.

Coverage under federal and NSW anti-discrimination law

A complaint under the ADA about the refusal to reconstruct a body after an autopsy to allow viewing of the body of a deceased person with hepatitis C is unlikely to succeed as a complaint of discrimination, as such circumstances are not currently covered by the ADA. The reason this is the case relates to the definitions of ‘relative’ and ‘associate’ under the ADA. This has been considered in detail above in relation to funeral services.

If the definitions of ‘relative’ and ‘associate’ in ADA are amended as proposed, it is arguable that where a person is refused the opportunity to view the body by virtue of the refusal to reconstruct a body after autopsy, such conduct may amount to direct disability discrimination under the ADA and the DDA. The ADA and the DDA provide specific exceptions in relation to discrimination on the ground of disability, where the disability is an infectious disease, and the discrimination is necessary to protect public health. The service provider would need to demonstrate that such evidence justifies the refusal to reconstruct bodies with hepatitis C as reasonably necessary to protect public health. There is evidence that this is not the approach taken by other providers in NSW and other jurisdictions.

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283 ADA, section 49P; a comparable section also exists in the DDA, section 48.
Conclusions and recommendations

Evidence to the Enquiry indicates that:

- the NSW Institute of Forensic Medicine (Glebe Morgue) has a policy of not reconstructing the bodies of deceased persons with hepatitis C after autopsy and that in cases where viewing of the body is not arranged prior to autopsy, family and friends may be denied the right to view the body.
- the policy of the NSW Institute of Forensic Medicine appears to be inconsistent with current autopsy policies and practices elsewhere in NSW and other jurisdictions.

The Enquiry recommends that:

53. Central Sydney Area Health Service determine whether the NSW Institute of Forensic Medicine’s policy has been to refuse to reconstruct bodies where the deceased is known or suspected of being hepatitis C infected.

54. Central Sydney Area Health Service ensure that the Division of Laboratory Medicine, undertaking the work of the Institute of Forensic Medicine, develops and implements a policy on reconstruction of bodies which provides that every effort is made to ensure that the viewing of bodies occurs before an autopsy takes place and, where viewing has not occurred prior to autopsy, that the bodies of deceased persons are reconstructed to enable family and friends to view the body where requested.

55. NSW Health ensure that the proposed statewide statutory authority, the Forensic Medicine and Pathology Authority, once established, develops and implements a policy on reconstruction of bodies which:

- applies to all agencies within the jurisdiction of the Forensic Medicine and Pathology Authority
- provides that every effort is made to ensure that the viewing of bodies occurs before an autopsy takes place and, where viewing has not occurred prior to autopsy, that the bodies of deceased persons are reconstructed to enable family and friends to view the body where requested.

56. NSW Health’s draft infection control policy is amended to provide that every effort is made to ensure that the viewing of bodies occurs before an autopsy takes place and, where viewing has not occurred prior to autopsy, that the bodies of deceased persons are reconstructed to enable family and friends to view the body where requested.

2.8 Educational settings

Evidence to the Enquiry indicates that discrimination occurs in educational settings. Where information about hepatitis C is provided in educational settings, it is not always accurate and the manner in which the information is provided may lead to the stigmatising of people who have hepatitis C and those most at risk of infection. As is common in other settings such as health care and employment, the evidence indicates that educational institutions may have inadequate policies and procedures in place to ensure the confidentiality of people with hepatitis C when they disclose their status or when their status becomes known. So too, the evidence indicates that it is not uncommon for teachers to have poor knowledge of hepatitis C transmission and inadequate knowledge of standard infection control procedures. Poor policies and procedures, coupled with a lack of knowledge about hepatitis C transmission, often fuel discrimination against people with hepatitis C. The interplay between breaches of confidentiality, poor knowledge of hepatitis C transmission and poor infection control procedures, and the consequences which often flow for people with hepatitis C have already been considered in detail, particularly in relation to employment and health care settings: see sections 2.3 and 2.4. Therefore this section simply outlines the evidence of these issues in education settings.

Disclosure and confidentiality

As is clear from earlier discussions, the need for confidentiality is of vital importance for people with hepatitis C. This is no less true in educational settings. Generally, people with hepatitis C are not required to disclose their status. Nonetheless, people do disclose their status in educational settings and the evidence indicates that breaches of confidentiality do occur as a consequence.
A mother told the school principal that her daughter was hep C positive. Her daughter had no problems at that school but when they changed schools, the principal rang the new school and told them that the child had hep C.

I disclosed my hepatitis C status to my daughter’s school principal. I asked him to keep it confidential. My daughter changed schools later that year. The new school principal approached me and told me that he was aware that I had hepatitis C. He asked me about the implications of having hepatitis C and working in the canteen. I couldn’t believe that the other principal had shared this information with someone else without my permission. It was no one’s business but mine. I felt really upset by the whole incident. I no longer volunteer my services at the school.

The rationale of breaches of confidentiality in educational settings occurs as a result of fears about students and staff being exposed to the risk of hepatitis C transmission, often based on a poor understanding of the risks associated with hepatitis C transmission.

Infection control procedures

As previously outlined, standard infection control procedures are designed to be routinely applied, regardless of whether a person is known or assumed to have hepatitis C. Given that approximately 40% of people in NSW who have been exposed to hepatitis C are unaware of their status, infection control measures based on assumptions or knowledge about a person’s hepatitis C status would be ineffective in reducing the risk of transmission. Standard infection control procedures, consistently applied, also ensure that people with hepatitis C are not required to disclose their status and that where a person’s status is known, there is no need for it to be disclosed to others in the misguided view that this is necessary for infection control purposes.

Despite clear policy in this relation to infection control, evidence to the Enquiry indicates that there is often:

- inadequate knowledge about hepatitis C transmission among students and staff
- lack of or poorly implemented standard infection control procedures.

The NSW Department of Education and Training (NSW DET) recently released a policy relating to prevention of transmission of hepatitis. The Enquiry strongly supports context-specific infection control policies and recognises that such policies, combined with effective implementation strategies, make an important contribution to ensuring standard infection control procedures are applied. This in turn reduces the likelihood of perpetuating the practice of people with hepatitis C being required to disclose their status, and the often adverse consequences which flow from such disclosure.

However, the Enquiry has heard that the NSW DET’s policy contains a number of critical inaccuracies, which stem from a lack of clarity in the policy between the different modes of transmission between hepatitis A, B and C. The NSW DET’s policy states:

Staff who are carriers of the hepatitis virus will:

- keep cuts and abrasions well covered with waterproof dressings;
- take the utmost care with their personal hygiene, regularly washing their hands, not sharing whistles, not sharing cups or eating utensils unless washed with water and detergent before use.

The concerns in relation to this are twofold. Firstly, as outlined in section 2.3, standard infection control procedures must be applied, regardless of whether a person is known or assumed to have hepatitis C. Secondly, the reference to ‘hepatitis viruses’ generally, may further the incorrect view that hepatitis C is

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284 Mr Stuart Loveday, Executive Officer, HCC NSW, Sydney hearing, 15 March 2001.
285 TRAIDS, Submission No. 61.
286 Health care worker, Submission No. 84.
288 Mr Stuart Loveday, Sydney hearing, 3 August 2001.
Hepatitis C education in secondary schools

The rate of hepatitis C diagnosis over the past five years has doubled among people aged 15 to 19 years from 54 per 100,000 population in 1996 to 108 per 100,000 population in 2000. The NSW Hepatitis C Strategy identifies young people as a priority group and schools as a key site for hepatitis C education. While such education is clearly of importance in relation to hepatitis C prevention, schools are identified as the most comprehensive and efficient means of access to the general community.

Secondary schools have been identified as an important setting for health interventions because:

- most of the population can be reached through secondary schools, particularly under year 10
- there is an established infrastructure to support health interventions
- school-based health promotion is relatively inexpensive

The significance of school-based hepatitis C education is further highlighted because school-based programs may be the only reliable and trusted source of information for many students, particularly for students from culturally and linguistically diverse backgrounds.

Evidence to the Enquiry suggests that there is a need to improve the levels of knowledge about hepatitis C among teachers and students.

My dad has HCV. I told my teacher when we were discussing diseases in class. My teacher told me after class that I needed to be careful not to share cups with dad. I told her she was wrong and I know about transmission of HCV. She said I didn’t know what I was talking about. The other students said the teacher must be right. I think some of my friends don’t come around (to my house) any more. Dad went to the school and gave my teacher information from the Hep C Council.

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289 Mr. Stuart Loveday, Sydney hearing, 3 August 2001.
290 The ADB has subsequently raised with NSW DET its concerns regarding the DET policy as outlined in evidence to the Enquiry. DET advises they are revising the policy in light of the issues raised. Personal communication with Personnel Programs Unit, DET, September 2001.
293 NSW Hepatitis C Strategy, at pages 12 and 17.
296 Individual Submission No. 48.
The young people I see have a complete blank, absolute and total blank as far as HCV is concerned…they all
know what HIV is but a lot of them have never heard of HCV even though a large proportion of them are
injecting drug users.297

The evidence is consistent with research findings in relation to both students’ and teachers’ levels of
knowledge about hepatitis C. A 1998 study of secondary school students found that young people had poor
knowledge about hepatitis C. This contrasts dramatically with consistently high levels of knowledge about
transmission of HIV demonstrated by the 1998 study and other studies.298 A survey of NSW high school
students in 2000, found that generally knowledge of and understanding of hepatitis was quite poor. Whereas
the majority of students correctly identified injecting drugs as a risk, sexual contact is falsely perceived by
most students to be the most common way of transmitting hepatitis C.299

A national survey of secondary school teachers found that:

- fewer than half reported that their school provided any hepatitis C education for the students
- only one in ten actually taught hepatitis C at their school, with a little appropriate professional
development
- knowledge levels for hepatitis C varied, with some areas of misinformation such as confusion
between hepatitis C and HIV transmission and that sexual contact is the most common transmission
route for hepatitis C
- there was a degree of uncertainty about whether students with hepatitis C should be allowed to play sport
or stay in school
- responses to questions about school policy and infection control guidelines revealed a lack of awareness
on the part of many teachers.300

The NSW Hepatitis C Strategy provides that NSW Health will work with the Department of Education
Training to provide appropriate hepatitis C prevention and education programs, for teachers and school
students, in schools.301 The Enquiry is aware that the NSW DET is currently developing appropriate
curriculum support materials for secondary students related to hepatitis. No further information was
available from NSW DET about this proposed resource at the time of writing. The Enquiry welcomes this
initiative in light of evidence to the Enquiry and research which indicates that there may be poor knowledge
about hepatitis C among teachers and students.

ANCAHRD has developed a national framework for education about hepatitis C, HIV/AIDS and sexually
transmissible infections (STIs) in secondary schools.302 The framework document emphasises the importance
of teaching students about hepatitis C and other blood-borne viruses within the broader social context in
which STIs, hepatitis C and HIV/AIDS are situated, rather than narrowly focusing on disease prevention.
Such an approach requires that information about hepatitis C is incorporated within both drug education
and health promotion, rather than taught as a stand alone education initiative. Yet, the national survey of
secondary school teachers found that where hepatitis C education programs are conducted in schools,
they are most likely to be taught in health education classes and least likely to be taught in drug education
classes.303 The national framework for education also emphasises that it is crucial that students have the
opportunity to explore values, attitudes and myths associated with STIs, HIV and hepatitis C so that
school-based programs do not isolate knowledge from the broader social context. Such an approach
would make a valuable contribution to reducing discrimination against people with hepatitis C.

Coverage under federal and NSW anti-discrimination law

As previously outlined, federal and NSW anti-discrimination laws prohibit discrimination against a person
on the basis of their HCV status, in specific areas of public life covered by the legislation, including in
educational settings.304

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298 Lindsay, J. et al., Uncertain knowledge: a national survey of high school students’ knowledge and beliefs about hepatitis C, at page 138.
301 NSW Hepatitis C Strategy at page 17 and 19.
302 Talking sexual health: National framework for education about STIs, HIV/AIDS and blood borne viruses in the secondary schools,
304 ADA, section 49L; DDA, section 22.
The ADA provides that it is unlawful for an educational authority to discriminate against a person on the basis that they have hepatitis C:

- by refusing or failing to accept his or her application for admission as student
- in the terms on which it is prepared to admit him or her as a student.

The ADA also provides that it is unlawful for an educational authority to discriminate against a student on the basis that they have hepatitis C:

- by denying him or her access, or limiting his or her access, to any benefit provided by the educational authority
- by expelling him or her
- by subjecting him or her to any other detriment.

However, the above provisions do not cover private educational authorities.305 The DDA also provides that it is unlawful for an educational authority to discriminate against people applying for admission and students in similar terms to the ADA.306 However, no exception exists for private educational authorities.

The NSW Law Reform Commission’s report (LRC) has undertaken an extensive review of the ADA and reported to the Attorney General in 1999.307 The LRC’s report has recommended that the broad exception for private educational authorities be repealed. The Enquiry supports this view.

Conclusions and recommendations

The Enquiry concludes that:

- there is a need for a stronger and more integrated policy response to hepatitis C education in schools
- efforts need to be made to improve policies and procedures in relation to standard infection control and confidentiality in NSW educational institutions
- school-based education needs to address the stigma and discrimination associated with hepatitis C and its relationship to injecting drug use.

Infection control

The Enquiry recommends that:

57. NSW DET’s Prevention of transmission of hepatitis policy is amended to ensure that standard infection control procedures are applied regardless of whether a staff member or student is known to have hepatitis C and the document accurately reflects the differences between the modes of transmission for hepatitis A, B and C.

58. NSW DET support the amended policy with an implementation strategy to ensure that the policy is implemented within educational institutions.

59. Educational institutions report to NSW DET on steps taken to implement the policy within 12 months of the policy’s release.

Confidentiality and privacy

The Enquiry recommends that:

60. NSW DET develop clear and accessible privacy and confidentiality guidelines which ensure that DET complies with their obligations under the NSW PPIP Act and that appropriate strategies are in place to protect the confidentiality of staff and students with hepatitis C.

61. NSW DET support privacy and confidentiality guidelines with an implementation strategy to ensure that the policy is implemented within educational institutions.

62. Educational institutions report to NSW DET on steps taken to implement the policy within 12 months of the policy’s release.

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305 ADA section 49L(3).
306 DDA, section 22.
Secondary school education

The Enquiry notes that NSW DET is currently developing curriculum support materials for secondary students related to hepatitis.

63. In formulating the curriculum for secondary students related to hepatitis the Enquiry recommends that:

- consideration is given to the National framework for education about STIs, HIV/AIDS and blood borne viruses in secondary schools and the NSW Survey of High School Students 2000
- the curriculum enables students to examine the values, attitudes, stereotypes and myths associated with hepatitis C transmission, people who have hepatitis C and those most at risk of infection
- the curriculum addresses discrimination against people who have hepatitis C or are thought to have hepatitis C and discusses anti-discrimination laws
- the curriculum ensures students are taught how to be blood aware and adopt standard infection control guidelines in all situations where blood is present.

Anti Discrimination legislation

64. The NSW Government repeal the broad exception for private educational authorities in the ADA.

2.9 Accommodation

There were two submissions to the Enquiry which raised issues regarding discrimination in the provision of accommodation, including the rejection of applications for private rental accommodation. Evidence to the Enquiry indicates that the rejection of applications for rental accommodation appears to be on the ground of assumed drug use, rather than on the basis of a person's hepatitis C status. Examples of alleged discrimination in the provision of accommodation suggest that people may be being discriminated against on the basis of their appearance, that is that a person 'looks like a drug user'. There was insufficient evidence provided to the Enquiry on this issue for the Enquiry to make any recommendations.

Coverage under federal and NSW anti-discrimination law

Generally, the ADA and the DDA provide that it is unlawful to discriminate against a person with a disability in the provision of accommodation. Such issues raise particular difficulties in relation to coverage under the ADA and problems of proof. While a real estate agent is entitled to choose between competing applications for the premises, it is unlawful to do chose one person over another on discriminatory grounds. The basis for the decision to rent a premises to one person rather than another can often be difficult to determine, for example, where real estate agents refuse to provide any reasons for their decision to refuse to rent a premises to a particular person, or state that the premises has been let to a more suitable person.

The ADA does not cover discrimination on the basis of physical appearance. As previously outlined, it remains unclear whether drug dependency or assumed drug dependency may amount to a disability under both the ADA and DDA: see section 2.2. However, should drug dependency or assumed drug dependency amount to a disability under the ADA and DDA, it is arguable that where a person, for example, is refused accommodation, there may be a basis for complaint under anti-discrimination law. Nonetheless, there are commonly problems of proof. In the case of the private rental market, an agent is entitled to chose between competing applications for a particular premise, as long as they do not discriminate between particular applicants on discriminatory grounds.

Conclusions

The Enquiry concludes that there is inadequate evidence to determine the extent of discrimination in accommodation against people who use drugs, have used drugs or are assumed to use drugs, particularly given the problems of proof which are commonly associated with allegations of discrimination in the private
rental market. Given that there was insufficient evidence provided to the Enquiry regarding discrimination in the provision of accommodation, no recommendations are made on this issue.

2.10 General community — family, friends, communities and media

If the whole community was educated about hep C I wouldn’t feel such a need to keep it a secret from my family and friends — the burden of this feels huge at times.

Attitudes of family and friends

While many submissions outline experiences of discrimination which have a significant impact on the lives of people with hepatitis C, some of the most painful stories relate to people’s experiences of being shunned and ridiculed by their own friends, families and communities. This can lead to increased social isolation and a lack of adequate support. The experience of being diagnosed with hepatitis C is often a very distressing experience, and people are most in need of support from the people they are close to. Yet it is all too common for people to be denied that support. Disclosure of a person’s hepatitis C status has led to relationship breakdowns. A person who was hepatitis C positive was not allowed to hold, play with or touch their new born niece.

I lost many friends over disclosing my status — I would not make the same mistake again. I never disclosed to family until 2 years after I was diagnosed. I was concerned they would discriminate. I was correct. For example, when greeting my nieces and nephews their parents noted if I would kiss the children on the lips and panicked if their children ever picked up my drinking glass…as my family has learnt more about hep C, they have become more supportive.

A 20 year old woman on combination therapy kept her medication supplies hidden in [an] esky under her bed. She remains very concerned about the potential for a negative reaction of her family members if she were to disclose that she had HCV. Consequently, she is undergoing treatment without the physical and psychological support of her family.

Stigmatisation within communities

Communities to which people with hepatitis C belong also often fail to provide a supportive environment. Evidence indicates that the disclosure of a person’s status can lead to harassment in local communities.

A man who is involved in his local church had told only a few people that he has hepatitis C. Unexpectedly, the priest approached him and asked him to refrain from going to communion or at least to go last. The man explained to the priest that no-one in the congregation was at risk of contracting hepatitis C. The priest still insisted that he either refrain or go last at communion. Feeling dissatisfied at the priest’s views he asked to have an appointment to discuss the situation. The priest has avoided meeting with him.

Family friends had decided that the children of a mother who has hepatitis C wouldn’t be allowed to play with their children any more or swim in their pool.

311 Individual Submission No. 75.
312 Individual Submission No. 7.
313 Individual Submission No. 8.
314 Hepatitis C Helpline caller, HCC NSW, Submission No. 80.
315 Individual Submission No. 94.
316 Individual Submission No. 32.
317 Health care worker, oral submission, Sydney hearing, 3 August 2001.
318 HCC NSW, Submission No. 80.
319 Hepatitis C Helpline caller, HCC NSW, Submission No. 80.
A sporting team was trying to get rid of one of their members who was in charge of the oranges at half time, someone had access to his medical information so a health professional let the team know that the person was HCV+ and they barred him from handling food.\(^{320}\)

The Enquiry has also received a number of submissions which provide case examples where a person’s hepatitis C status has been used by one partner against another in family law proceedings as a reason for preventing access to children of their relationship, following separation. A recent study involving 466 women with hepatitis C, found that 6\% of women reported that as a result of their hepatitis C status, access to their children was threatened.\(^{321}\)

...My son’s solicitors received a letter from his estranged wife’s solicitors regarding visitation rights and his children. The letter stated that if visiting rights to the father of the children were to be granted they would require ‘an undertaking that the children would not be taken to their paternal grandmothers’. They argued in their letter that there was some concern that the grandchildren might contract a communicable disease, such as hepatitis C, from the grandmother.\(^{322}\)

Negative and unsupportive responses by partners, friends and families have a significant impact on the lives of people living with hepatitis C and can exacerbate feelings of isolation and stigmatisation.

**Media**

While the media can and does play a vital role in promoting public awareness and education about hepatitis C to the general community, and assist in creating an environment that is supportive and understanding of people with hepatitis C, it can also play a part in providing inaccurate information and fueling stereotypes that cause discrimination against people with hepatitis C.

In some instances misinformation may not be intended to promote the stigmatisation of people with hepatitis C, but such misinformation can be particularly significant given the power of television in particular. The Hepatitis C Council of NSW outlined a number of circumstances where television drama programs have reinforced incorrect information about the transmission of hepatitis C and the obligations of people to disclose their status. One such example was an episode of *All Saints* which aired at the end of November 2000. A character on the program had hepatitis C and had not informed hospital staff. The doctor was angry with the patient because the patient had not informed hospital staff that he had hepatitis C and berated him for putting surgeons and other theatre staff at risk of contracting hepatitis C. Such information undermines the continuing efforts to ensure that health care workers, employers and people with hepatitis C understand the importance of standard infection control procedures. Generally, people with hepatitis C are under no obligation to disclose their status in health care settings for the purposes of infection control. An episode of *Peak Practice* in December 2000 stated that hepatitis C is a sexually transmitted disease. While it is possible for hepatitis C to be sexually transmitted where there is blood-to-blood contact, the current evidence suggests that this occurs only in rare instances. Hepatitis C testing is not routinely recommended following unprotected sex.\(^{323}\)

Evidence to the Enquiry also demonstrates the damaging role the media has played in undermining community support for important hepatitis C prevention initiatives, such as needle and syringe programs. On occasions the media appear to play an active role in creating and reinforcing community fears that needle and syringe programs lead to poor needle and syringe disposal, despite the fact that there is no evidence that needle and syringe programs increase the number of needles and syringes discarded in public places.\(^{324}\) This appears to

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\(^{321}\)Professor Sandy Gifford, Submission No. 94.

\(^{322}\)TRAIDS, Submission No. 61.

\(^{323}\)Stuart Loveday, Sydney hearing, 15 March 2001. The Enquiry reviewed the article referred to in evidence and found the pictorial representation of the syringe to be an gratuitous and utterly inappropriate.

\(^{324}\)Personal communication with Stuart Loveday, Executive Officer, HCC NSW, 9 August 2001.

be particularly common in relation to regional papers. A number of health workers in regional locations reported incidents where they allege that local media had placed needles and syringes in public locations for the purpose of photographing examples of poor disposal. This in turn fuels stereotypes about the irresponsible behaviour of people who inject drugs and undermines community support for prevention programs.

We get a lot of bad press from the local newspaper particularly regarding the NSP program. We get a lot of bad press from the local newspaper particularly regarding the NSP program. The media really love pictures of syringes. They’ll open a fit pack box which is brand new and pull out a syringe so it makes it look like it’s all wonderful for the newspaper ... just to make sure that they get a good photo shot. ... We’re set up with needles all the time, all of a sudden they’re there, and within minutes so is the media. Initiatives such as the Hepatitis C Council’s Brief media guide and The Australian media guide to hepatitis C are important resources that support accurate reporting about hepatitis C and encourage terminology that does not stigmatise people with hepatitis C.

Coverage under anti-discrimination law

As outlined in Chapter 1, anti-discrimination laws prohibit discrimination on the ground of disability in the various areas of public life covered under federal and NSW anti-discrimination law, such as employment, education, accommodation and the provision of goods and services. Many of the examples of discrimination by partners, families, friends and communities do not fall within the ambit of anti-discrimination law. However, the existence of laws which prohibit discrimination against people living with hepatitis C and HIV do play a broader educative role. There is undoubtedly room for further community education.

Vilification is a public act that could incite others to hate, have serious contempt for, or severely ridicule a person or group of people. The ADA prohibits vilification on the basis of:

- race
- homosexuality
- HIV/AIDS
- transgender status.

In terms of disability vilification, currently the ADA only covers vilification on the basis of HIV/AIDS and there is no coverage for hepatitis C related vilification. In contrast, the Tasmanian Anti Discrimination Act 1998 prohibits disability vilification.

Current and proposed community education initiatives

It is important to acknowledge the significant steps taken in recent years to address the level of community understanding about hepatitis C. In particular, in March 2000 NSW Health implemented a mass media hepatitis C public awareness campaign consisting of prime time television advertisements, posters, ethnic and Indigenous radio and press, information brochures, and support activities in Area Health Services.

The objectives of the campaign were to:

- reduce discrimination against people with hepatitis C
- create an environment supportive of hepatitis C programs
- increase awareness of hepatitis C
- decrease the misinformation about hepatitis C.

The initial evaluation of the campaign indicates positive effects among NSW adults. Specifically, the first

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326 Regional hearing, May 2001
330 ADA, racial vilification — sections 20B–20D; transgender vilification — sections 38R–38T; homosexuality vilification — sections 49ZS–49ZTR; and HIV/AIDS vilification — sections 49ZXA–49ZXC.
331 Anti-Discrimination Act 1998 (Tas.), section 19.
332 Bauman, A. and Chen, J. 2001 NSW hepatitis C media campaign evaluation 2000 — Report 1, Results of the impact of the hepatitis C campaign in NSW from cohort and independent sample population surveys, Australian Centre for Health Promotion.
phase evaluation indicates that the outcomes included:

- increased knowledge of the risk of modes of transmission of hepatitis C
- improved knowledge of the difference between hepatitis C and hepatitis B
- improved understanding of the numbers of Australians with hepatitis C
- improved understanding that injecting drug users are not the only group affected by hepatitis C
- increased agreement that needle and syringe programs are required to reduce the number of new infections

The campaign evaluation comprises six elements, the above first phase evaluation encompasses two of these elements. The remaining evaluation includes an evaluation of the campaign by analysing calls to the Hep C Helpline and a GP survey.

The NSW Parliamentary Inquiry played a significant role in raising the profile of hepatitis C related issues within the general community and government. The conduct of this Enquiry has also provided an important opportunity to raise awareness of hepatitis C related discrimination among the general community, service providers, the media and government. The Enquiry hearings have received extensive media coverage and media reports have assisted in bringing to public consciousness the nature and impact of discrimination against people with hepatitis C. Appendix B details the media coverage of the Enquiry hearings.

The ADB has an ongoing role in informing and educating the people of NSW, employers and service providers about their rights and responsibilities under anti-discrimination law, including hepatitis C related discrimination.

The Australian Hepatitis Council has recently prepared a national *Hepatitis C Anti-Discrimination Strategy 2001–2004* (the Strategy). The Strategy was developed through consultation with key stakeholders throughout Australia. Consultations were conducted with representatives from Hepatitis C Councils, Health Departments, peer-based injecting drug user groups, haemophilia foundations, HIV/AIDS organisations, researchers, and anti-discrimination and human rights organisations. The Strategy acknowledges that hepatitis C related stigma and discrimination are complex phenomena, and that preventing and reducing both will require a long-term, multi-pronged approach. One of the key strategic objectives is the conduct of a national hepatitis C social marketing campaign which aims to increase hepatitis C awareness and thereby contribute to reducing discrimination. Should this strategy be implemented, NSW would stand to benefit from a social marketing campaign which would build upon the national campaign, without dedicating funds to a further campaign. It is important to note that implementation of the Strategy is dependent upon the availability of funding, and at the time of writing, no decisions regarding funding of the Strategy had been made.

### Conclusions and recommendations

**Community education**

Evidence to the Enquiry demonstrates that two main factors contribute to discrimination against people with hepatitis C, the first is that a lack of understanding about the modes of transmission for hepatitis C often leads to discrimination because of unfounded fears about the infectiousness of hepatitis C. The second is the complex interplay between hepatitis C and injecting drug use, which results in people with hepatitis C being discriminated against on the basis of actual, past or presumed drug use.

As outlined, there has been a recent mass media campaign in NSW and a national campaign is proposed, subject to availability of resources. The initial evaluation indicates the NSW campaign has made a contribution to improving general community understanding about the modes of hepatitis C transmission. However, there are limits to the extent to which knowledge of hepatitis C transmission alone will assist in eliminating discrimination against people with hepatitis C, given the clear link between stigmatisation of drug use and hepatitis C related discrimination. The Enquiry is of the view that should a social marketing campaign be undertaken, reducing stigmatisation associated with injecting drug use should be a primary aim. However, there was insufficient evidence before the Enquiry to determine whether a social marketing campaign would be effective in addressing hepatitis C related discrimination. Given this, the Enquiry does not make recommendations in relation to general community education.

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The Enquiry considers that any additional resources that may be harnessed as a result of the recommendations in this Report would be best allocated to specific educational initiatives outlined in this report, including:

- targeting discrimination in the workplace and health care settings, as outlined in recommendations in sections 2.3 and 2.4
- an anti-discrimination advocacy program designed to enhance the capacity of community-based organisations such as the Hepatitis C Council of NSW and NUAA to undertake individual advocacy to assist people in accessing and using anti-discrimination and other complaint mechanisms, as outlined in Chapter 4.

Anti-Discrimination Act

There is evidence to suggest that serious harassment and vilification of people with hepatitis C does occur. The ADB, in its submission to the Attorney General on the review of the ADA, expressed the strong view that a need exists to address the public vilification of people with disabilities. The ADB has recommended the extension of the coverage of vilification under the ADA to people with disabilities. Evidence from this Enquiry adds weight to the view that issues around public violence and abuse against people with hepatitis C must be addressed as a matter of urgency.

The Enquiry recommends that:

65. The NSW Government amend the ADA to include vilification against people with disabilities, including hepatitis C, which covers conduct that is offensive, insulting, humiliating or intimidating.
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 sure.

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.

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.

In 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.

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.

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 in 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 of no different from other people in the community, except they inject drugs.

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. 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 are 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.

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

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2 See Chapter 2, section 2.2 for a detailed discussion.
3 HCC NSW, Submission No. 80.
4 Lenton, S. Not all drug injectors are addicts - New Study, Media Release, Curtain 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... 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. 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.

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.

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. 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’.

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.

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.

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

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1 Individual Submission No. 46.
2 See Appendix E at section C2.
3 Examples include: HCC NSW, Submission No. 80; NUAA, Submission No. 68; AIVL, Sydney hearing, 2 August 2001; and ANCAHRD HCV Committee, Submission No. 47.
4 AHC, Submission No. 60.
5 National Hepatitis C Strategy at page 48 and NSW Hepatitis C Strategy at page 24.
7 The Kirketon Road Centre is a specialist drug and alcohol service.
8 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

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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

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

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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

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19 Health care worker, regional hearings, May 2001
20 Dr A. R. MacQueen, Submission No. 97.
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 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
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…

Another regional health care worker stated that the Area Health Service was not prepared to put their logo on the flaps 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.

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.

Aboriginal people accessing Aboriginal organisations is another obstacle. There are fears around confidentiality.

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.

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.

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.

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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 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
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

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49Dr Ingrid van Beek, Sydney hearing, 2 August 2001.
50Health care worker, Dubbo hearing, 16 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.

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

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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

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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.
71 Multicultural HIV/AIDS Service, Submission No. 64.
72 NSW Hepatitis C Strategy, at page 12.
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.

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

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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.
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

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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.
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. 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.

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. 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.

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.

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85 HCC NSW, Submission No. 80.
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.

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89 Individual Submission No. 4.
90 Individual Submission No. 46.
91 NCHSR social analysis of evidence to the Enquiry: see Appendix E.
chapter 4

Avenues for redress
4.1 Access to and use of complaint mechanisms

Avenues for complaint

Anti-discrimination legislation prohibits disability discrimination in many areas of public life, however the treatment that individuals experience as discriminatory or unfair may not necessarily amount to unlawful discrimination under anti-discrimination law. Although some of the evidence to the Enquiry raises issues which fall outside the ambit of anti-discrimination law, it appears likely that many of the examples of discrimination presented to the Enquiry could be covered by anti-discrimination and/or a range of other avenues for complaint. Consideration has already been given to coverage under anti-discrimination and health care complaints legislation in the course of considering evidence to the Enquiry; see Chapter 2. A variety of other legal avenues for redress may also be appropriate, depending on the circumstances, such as unfair dismissal proceedings under federal or NSW industrial legislation and complaints under privacy legislation. Federal and NSW privacy legislation is examined in more detail in section 4.2 below.

Hepatitis C complaints under anti-discrimination legislation

The functions of the ADB are broad ranging, including the conduct of public inquiries, research, and educational activities designed to eliminate discrimination, promote equality and support compliance with anti-discrimination law. The ADB also investigates and, where possible, conciliates individual complaints lodged under the ADA. Evidence to the Enquiry indicates that discrimination against people with hepatitis C is commonplace. Many of the examples of discrimination raised are likely to be covered by anti-discrimination legislation, yet few complaints of hepatitis C discrimination are lodged under either the DDA or ADA.

As previously outlined, hepatitis C is a disability within the meaning of the DDA. Complaints of disability discrimination under the DDA are lodged with HREOC. HREOC collects statistics for complaints and telephone enquiries under the category of ‘other organisms causing disease’, which include hepatitis C related complaints or enquiries. Anecdotally, HREOC indicates that complaints and inquiries in this category relate mainly to hepatitis B or C related discrimination. Between June 1999 and June 2001, HREOC received 252 telephone enquiries regarding hepatitis C related discrimination, however only 23 complaints were lodged: see Table 2 below.

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<tr>
<th>TABLE 2: Number of complaints lodged and telephone enquiries — Disability Discrimination Act*</th>
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<td><strong>Complaints — organisms causing disease</strong></td>
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<td><strong>Total DDA complaints</strong></td>
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*Complaint statistics are based on a voluntary demographic survey, with a return rate of between 60–70%.

**Category of organism causing diseases includes mainly hepatitis C or B matters

Source: HREOC

1 Cabassi, J. Barriers to access and effective use of anti-discrimination remedies for people living with HIV and HCV, ANCAHRD Occasional Paper No. 1, May 2001.

2 Personal communication with, Manager of Complaints Branch, HREOC, July 2001.
Complaints under the ADA are made to the ADB. The ADB does not collect statistics relating to hepatitis C separately from the general category of disability discrimination. However, anecdotally, hepatitis C related complaints made to the ADB are also low.

## Barriers to access and use of complaint mechanisms

Of all submissions received from individuals, only 16% reported that they had taken any action in response to the incidents of discriminatory or unfair treatment raised in their submissions. Of those that did take some form of action, the most common avenues of complaint were:

- local Member of Parliament
- internal complaint mechanisms of the service or government department.

For example, a number of people indicated they had lodged complaints directly with the health care service provider, hospital or Area Health Service. Generally, people reported they were dissatisfied with the response they received, however, they did not take the matter further. Very few people indicated that they had pursued formal avenues of redress under anti-discrimination, health care complaints, privacy or industrial legislation.

Through participation in the Enquiry, many people have become aware of complaint options available under anti-discrimination and health care complaints legislation, and some people have also elected to lodge formal complaints about the issues raised in their submissions.

In relation to the available legal avenues for redress, many key community sector organisations have drawn attention to:

- the limitations of individual complaint mechanisms, both in achieving outcomes for individuals and in bringing about systemic change
- factors which act as disincentives to individuals using complaint mechanisms generally, and anti-discrimination complaint mechanisms in particular.³

There is a complex array of factors that influence people's access to and use of avenues of complaint.

Individual complaints under anti-discrimination legislation require that individuals understand their experience as discrimination, and have sufficient information and resources to use the complaint mechanisms available. The evidence indicates that many people with hepatitis C are unaware of the options available to them when they believe they have been discriminated against. When people experience discrimination in one form or another with such regularity that it is somehow normalised, they are unlikely to consider taking action about discriminatory treatment because they do not identify it as unacceptable.

Most injecting drug users come to accept and even expect a certain level of discrimination in their lives. Sometimes they may not even recognise when discrimination is happening and if they do see it for what it is, they see it as something that they can’t change, and there certainly isn’t any point complaining about it.⁴

Stigmatisation and discriminatory treatment can also impact upon people’s perceptions of themselves, resulting in low self-esteem, thus undermining their capacity to take action. When one young man was asked why he did not complain, he replied:

> [I got] the virus through drug use, drug use is a criminal activity, therefore (they would think) I’m no good. I don’t feel self-respect, I don’t feel half the person anyone else does…one I’m a drug user, two I’ve got this disease.⁵

Cultural factors may also act as a deterrent to making a formal complaint. The Multicultural HIV/AIDS Service report that many people from culturally and linguistically diverse communities hold health professionals in high regard. This, in combination with language barriers, tends to contribute to a passive doctor–client relationship, which places doctors beyond challenge for many consumers.⁶

The ADA provides that a complaint may be made where a person is victimised as a result of lodging a complaint or intending to lodge a complaint under the ADA.⁷ Despite the capacity to lodge complaints of victimisation, the evidence indicates that concerns about confidentiality and the consequences of making a formal complaint often deter people from complaining.

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³ These issues were raised in a number of submissions including: Combined Community Legal Centre of NSW, Submission No. 58; AHC, Submission No. 60; Council of Social Service of NSW, Submission No. 76; and HCC NSW, Submission No. 80.


⁶ Multicultural HIV/AIDS Service, Submission No. 64.

⁷ ADA, section 50.
Given many people are fearful of public disclosure of their HCV status, there may be concerns that lodging a complaint will lead to public identification, which is an even greater concern in rural and remote NSW. A lawyer in a regional centre reported to the Enquiry that his clients often had strong cases, but were reluctant to proceed because they feared the consequences of doing so.

There is a real unwillingness to complain even when people are aware of their rights. The most obvious reason for this is fear of victimisation. In a small town where, for instance the hospitality industry, there may be 30 employers, it’s very easy to be black-listed for making a complaint. There aren’t many employers who don’t make it public knowledge that they’ve got somebody making a complaint against them. If you’ve lost your job and you’re in an area of high unemployment and there’s difficulty getting other employment, the idea of complaining and maybe getting some sort of redress in 12 or 18 months time just isn’t viable.

Fears about the potential consequences of complaining are also reflected in many individual submissions to the Enquiry.

‘Margaret’ had been terminated from her employment and had received legal advice that she had a good case in relation to a complaint of discrimination in employment. However, as she was now unemployed, she decided that she would not take action against her former employer because she would need a reference in order to obtain another job.

The NSW Combined Community Centre Group highlighted a number of factors which affect people’s use of anti-discrimination complaint mechanisms, including:

- the stress associated with proceedings and the implication that this may have for people’s health
- delays commonly associated with use of anti-discrimination complaint processes
- fears regarding the consequences of lodging a complaint, such as their hepatitis C status being disclosed
- the power imbalance between complainants and respondents
- the financial costs associating with pursuing complaints to a hearing where they are not resolved at conciliation.

Delays in the handling of complaints have been identified as a disincentive to people lodging complaints in the first instance, and as a significant factor in complaints being withdrawn prior to resolution. The evidence also indicates that there is often a significant imbalance of power between complainants and respondents, particularly in relation to the capacity of the parties to bear the costs associated with legal proceedings. This can lead to unsatisfactory settlements at conciliation or no resolution because it is anticipated that the complainant will be unable to proceed to a hearing.

I decided not to [proceed]…the directors are powerful people…I felt that they would fight extremely dirty in a lawsuit to defend their reputation. I was so traumatised by the experience that I didn’t have the energy to tackle them head on in court.

The NSW Combined Community Centre Group raise concerns about the capacity of individual complaints to adequately address systemic discrimination. Although complaints settled on confidential terms may provide for policy changes, conciliated settlements do not set a precedent for other similar cases. As is demonstrated by the above case study, individual cases may not result in systemic changes because individuals cannot afford to pursue the matter in

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1 HCC NSW, Submission No. 80.
3 Individual Submission No. 65.
4 Combined Community Legal Centre of NSW, Submission No. 58. For discussion of these issues see also Cabassi, J. Barriers to access and effective use of anti-discrimination remedies for people living with HIV and HCV.
5 Individual Submission No. 86.
6 Discrimination in the provision of insurance is considered in detail in Chapter 2, section 2.6.
7 Individual Submission No. 27.
8 Combined Community Legal Centre of NSW, Submission No. 58.
court due to high costs and pressure, resulting in no settlement being reached or poor settlement outcomes because individuals have no choice but to accept what is being offered.

**Improve access to and use of individual complaint systems**

In order for people to be able to use complaint mechanisms, people must be able to name their experience as one of discrimination, understand their rights under anti-discrimination law and have sufficient information and resources to utilise anti-discrimination laws as a means of addressing the discrimination they experience. Given the stigma associated with hepatitis C and drug use, people’s fears regarding disclosure of their hepatitis C status, and the diverse range of people affected by hepatitis C, people with hepatitis C are a particularly difficult group to target with information about their rights under anti-discrimination law and other legislation. However, the two key community-based organisations in NSW, the Hepatitis C Council and NUAA, are uniquely placed to create an effective interface between people affected by hepatitis C, and drug use related discrimination and anti-discrimination and other complaint systems. Such agencies already regularly provide advice and referral information regarding hepatitis C and drug use related discrimination though services such as the Hep C Helpline and Prisoners’ telephone advice service, individual and systemic advocacy, and education initiatives including publications such as Users News and Hep C Review.

The Hepatitis C Council of NSW’s Hep C Helpline received 4,355 calls during the financial year 1999–2000. Even at a conservative estimate, at least one in five phone calls to the Hep C Helpline were to discuss discrimination-related issues. NUAA’s advocacy team also provides a telephone advice service and reports that hepatitis C, drug use and drug treatment related discrimination comprise a large number of enquiries. The Enquiry considers that an advocacy program, designed to enhance the capacity of the Hepatitis C Council of NSW and NUAA to provide effective individual advocacy, would make an important contribution to improving individual’s access to and use of individual complaint mechanisms.

A recent initiative of ACON provides a useful model for such an advocacy program. The ADB, in conjunction with ACON, has designed and delivered an anti-discrimination advocacy program which focused on developing the capacity of staff to:

- identify discrimination issues as they arise in their work with individuals and groups by increasing knowledge of anti-discrimination law and processes
- support people to take action in response to discrimination by developing the individual advocacy skills of staff.

The training is then supported by ongoing focus groups to provide staff with opportunities to:

- discuss and reflect on their experiences in applying their knowledge and skills through their individual advocacy
- consolidate individual advocacy skills by sharing experiences in utilising complaint systems.

The program also incorporates an action research component. ACON, working in partnership with the Southern Cross University, is documenting and analysing the experiences of individuals using anti-discrimination complaint mechanisms, other legislatively-based complaint mechanisms and informal strategies for responding to discrimination. This action-based research will in turn improve the capacity of community based agencies to advocate for reforms appropriate to the needs of their communities.

The Enquiry considers that there is merit in, and a demonstrated need for, an anti-discrimination advocacy program which aims to:

- increase knowledge and skills of community-based organisation’s staff to enable staff to undertake individual advocacy with and for people who wish to take action in response to hepatitis C and drug use related discrimination
- build partnerships between relevant community based organisations and the ADB, HCCC, community legal centres and other relevant agencies to enhance community confidence in, access to and use of the anti-discrimination and other complaint systems
- increase the capacity of community based organisations to identify systemic discrimination and utilise this knowledge to bring discriminatory policies and practices to the attention of the President of the ADB, to enable him or her to exercise their power to initiate a complaint where such action is appropriate.
It is unlikely that this type of individual advocacy program can be achieved without additional resources for the Hepatitis C Council of NSW and NUAA.

**Improve capacity to respond to systemic discrimination**

In addition to improving the capacity of individuals to utilise anti-discrimination complaint mechanisms, it is also critical that the ADA is amended to improve the capacity of anti-discrimination law to address systemic discrimination, without reliance upon an individual to lodge a complaint.

The NSW LRC has undertaken an extensive review of the ADA. The LRC has recommended that the ADA be amended to:

- provide that the Minister may refer a matter to the President for investigation, without requiring that an individual complaint is lodged
- give the President the power to recommend to the Minister that a particular matter be referred for investigation.

The ADB has also advocated for the President to have the power to intervene in both original and appeal proceedings concerning discrimination, harassment or vilification in the Administrative Decisions Tribunal (ADT). The ADB has strongly advocated for the President to have the power to initiate complaints where he or she becomes aware of conduct that could constitute a contravention of the Act, but no complaint has been lodged. The ADB does not agree with the requirement that the Minister refer the matter. In making a decision to initiate a complaint regarding a matter of systemic discrimination and/or a matter of public interest the President must be able to act independently of government in his or her role as the administrator of NSW anti-discrimination law. The proposal for the President to have the power to initiate complaints is also analogous to the initiation powers currently exercised by statutory office holders like the Ombudsman and the Health Care Complaints Commissioner.

The ADB has also advocated for the President to have the power to intervene in proceedings concerning discrimination, harassment or vilification in the Administrative Decisions Tribunal (ADT). In the ADB’s view the President’s power to intervene in an application for an original decision and in an appeal panel matter should be ‘as of right’, rather than by leave of the ADT given that the President is responsible for administering the ADA and has developed considerable expertise as a result. The power to intervene as of right is also consistent with the President’s power to intervene in proceedings in the Industrial Relations Commission concerning unlawful discrimination under the ADA. Such powers are consistent with those available to the HREOC special purpose Commissioners. The Human Rights and Equal Opportunity Commission Act 1986 (Cth) has recently been amended to give an amicus curiae function in relation to both Federal Court and Federal Magistrates Court proceedings. The Enquiry also considers that the ADT Act should be amended so that the Appeal Panel can refer a question of law to the Supreme Court, for an opinion of the Court, at the request of the President.

**Conclusions and recommendations**

The Enquiry concludes that:

- anti-discrimination and other complaint-based systems are under-utilised by people with hepatitis C
- people with hepatitis C are often unaware of their rights under anti-discrimination law
- anti-discrimination complaint-based systems place a significant burden on individuals to enforce their rights
- people with hepatitis C face significant barriers in utilising complaint mechanisms provided by anti-discrimination and other legislation

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18 Such action is based upon the assumption that the ADA will be amended to provide the President with the power to initiate complaints, which is considered immediately following this subsection.
20 Review of the Anti-Discrimination Act 1977 (NSW), recommendation 125 at page 672.
21 Industrial Relations Act 1996 (NSW) (IRA), section 167(2). The IRA also gives the President power to intervene in Industrial Relations Commission (IRC) proceedings in a wide range of other circumstances such as intervening in an application to vary an industrial instrument (section 169(4)(b)). For other powers of intervention by the President in IRC proceedings — see sections 187(d) and 324(2)(d).
22 Human Rights and Equal Opportunity Commission Act 1986 (Cth), section 46PV. This section was amended by Act No. 194 of 1999 and the provision commenced operation on 13 April 2000.
The Enquiry considers that an anti-discrimination advocacy initiative, designed to increase the capacity of the Hepatitis C Council of NSW and NUAA to provide effective individual advocacy is most likely to improve the capacity of individuals to take action in response to discrimination. It is also essential that anti-discrimination legislation provides a legislative framework to enable systemic discrimination to be addressed without the necessity for an individual complaint to be lodged.

The Enquiry recommends that:

73. The Hepatitis C Council and NUAA, in partnership with the ADB, design and implement an anti-discrimination advocacy program to:
   - enhance the capacity of the Hepatitis C Council of NSW and NUAA to identify discrimination or unfair treatment actionable under anti-discrimination and other relevant legislation
   - support individual access to and use of anti-discrimination and other complaint mechanisms.

74. The NSW Government provide adequate resources to the Hepatitis C Council of NSW and NUAA to develop and implement the above program and provide ongoing individual advocacy services.

75. The NSW Government amend the ADA to enable:
   - the President to initiate complaints under the ADA
   - the President to intervene in applications for original decisions and Appeal Panel matters.

76. The NSW Government amend section 118 of the ADT Act so that the Appeal Panel can refer a question of law to the Supreme Court, for an opinion of the Court, at the request of the President.

77. The NSW Attorney General’s Department ensure that the ADB is provided with sufficient resources to:
   - enable the timely handling of complaints
   - take action to address systemic discrimination, such as initiating complaints and intervening in ADT proceedings.

4.2 Privacy legislation

Overview

Presently, there is no single, comprehensive piece of privacy legislation in NSW applying to the private and public sectors. Rather the legal framework applying to health information consists of a number of layers, and includes:

- privacy legislation in NSW applying to public sector agencies
- health-related legislation, with specific provisions on confidentiality
- federal privacy legislation for the private sector in Australia, which commences on 21 December 2001
- common law medical confidentiality obligations applying to the practitioner–patient relationship
- various laws requiring the mandatory reporting of information by practitioners, including public health and child protection legislation.

NSW legislation

The PPIP Act established the office of the Privacy Commissioner and introduced a set of 12 Information Protection Principles (IPPs) that regulate the way public sector agencies in NSW deal with personal information. The Act came fully into effect on 1 July 2000.

Under the PPIP Act, ‘personal information’ includes any information that relates to an identifiable person. It covers not only traditional paper files, but any other record that would reasonably allow a person to be identified, including electronic files. The IPPs cover the collection, storage, use and disclosure of personal information, as well as an individual’s right to access information held about them. IPP 12, set out at section
19 of the Act, provides special provisions limiting the disclosure of more sensitive types of personal information, including health information.

As outlined in Chapter 2, NSW Health has prepared a comprehensive Privacy Management Plan in accordance with the requirements of the PPIP Act and has also developed an Information Privacy Code of Practice. The Code will remain a central policy document for the way in which NSW Health handles personal information.

Role of the Privacy Commissioner in relation to complaints

The PPIP Act only provides legal remedies in relation to privacy breaches by public sector agencies. However, it does give the Privacy Commissioner power to investigate and conciliate complaints about breaches of privacy by organisations and individuals who are not public sector agencies. When complaints are made to Privacy NSW, the Privacy Commissioner decides whether the complaint should be investigated under Part 5 of the Act, that is the internal review is conducted by a public sector agency. The majority of matters are referred to the relevant public sector agency for internal review, because where complaints are investigated by the Privacy Commissioner, the complainant does not have the option to pursue the matter in the ADT, as is the case where investigation occurs under Part 5 of the PPIP Act. Where a complaint investigated by the Privacy Commissioner is not resolved, the Commissioner can make a report to Parliament in relation to the matter.

Under Part 5 of the PPIP Act, individuals have the right to seek a review by a public sector agency in cases where the individual believes the agency has breached their privacy. The primary responsibility for dealing with internal reviews lies with the agencies, although the Privacy Commissioner can undertake reviews for agencies if that agency requests the Commissioner to do so. Where an agency conducts the review, the Privacy Commissioner may also make a submission to the agency during the course of the review.

Remedies under the PPIP Act

Where internal review fails to resolve a complaint made under the PPIP Act, the complainant may take the matter to the ADT. The ADT may make orders requiring an agency to undertake certain remedies/action, including:

- to refrain from conduct or action which breaches an IPP or Code
- to correct information disclosed by an agency
- to take steps to remedy loss or damage.

The ADT may also make an order requiring an agency to pay damages up to $40,000 for loss or damage suffered where the applicant has suffered financial loss or psychological or physical harm as a result of the conduct.

Other NSW legislation

There is also a range of health related legislation which imposes privacy and confidentiality obligations on people working in the NSW health system. This legislation includes the Health Administration Act 1982, section 22, the Mental Health Act 1990, section 289 and the Public Health Act 1991, sections 75 and 17. As outlined in section 2.3, section 17 of the Public Health Act only applies to HIV.

Proposed legislative reform in NSW

It is important to note that one of the major limitations of the PPIP Act is that it only provides legal remedies in relation to privacy breaches by public sector agencies. However, the NSW Ministerial Advisory Committee on Privacy and Health Information (‘the Committee’) has recently proposed legislative reform which, if passed, would improve coverage of privacy legislation in relation to health information.

Report of the NSW Ministerial Advisory Committee on Privacy and Health Information

The Committee was appointed in June 2000 by the NSW Health Minister to investigate and advise on privacy issues relating to health information, particularly those raised by the proposed electronic health

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24 This only applies where the conduct occurred after 1 July 2001.
records system. The Committee was asked to provide recommendations and effective strategies to ensure that
NSW Health and its partners in health services delivery, ensure personal health information is collected,
stored and used in accordance with NSW and federal privacy principles.

The NSW Privacy Commissioner chaired the Committee. The Committee reported to the Minister for
Health in December 2000. The Committee made a range of recommendations, the most important of
which is that the system of linked electronic health records be governed by a separate and specific piece of
State legislation. The Committee has proposed that specific legislation dealing with privacy of health
information privacy be enacted.25

The Committee proposed that specific health information privacy legislation should be enacted
which would:

- apply to all health information, regardless of who possesses the information and what form the
  information is in
- specify the purposes, protocols and mechanisms for and by which records could be transferred or linked
- incorporate the IPPs set out in Part 2 of the PPIP Act
- provide for the right of inspection, access, copy, annotation and correction of any health record by the
  person who is the subject of the record, except in exceptional and specified circumstances
- empower the Privacy Commissioner to investigate and determine complaints, initiate and conduct
  investigations, enquiries, and make reports and recommendations to the Minister and Parliament, all
  under the Act
- impose substantial civil and criminal penalties for breaches
- incorporate all existing privacy and confidentiality requirements in existing statutes
- give specific recognition to particular problems related to the capacity of children to withhold information
  from their parent or guardian in particular circumstances.

Specific health information privacy legislation as proposed by the Committee is significant because if such
legislation was enacted it would cover health information regardless of who possessed it. This would extend
privacy legislation to private sector employers and health services, not currently covered by privacy legislation.
This is significant given that once a person's status becomes known, whether by voluntarily disclosure,
appropriate requirements for disclosure, or as a result of breaches of confidentiality in employment,
discrimination often follows. Adequate privacy protection for health information held by employers is critical
given that information about a person's hepatitis C status is highly sensitive and there are often adverse
consequences when a person's status is disclosed. This issue has been considered in detail in Section 2.4.

The NSW Government has indicated its support for the Committee's recommendations.

Federal Privacy Act

The Privacy Act 1988 (Cth) applies to information held by Commonwealth and ACT public sector agencies.
The Act is based around 12 IPPs on collection, storage, use and disclosure of personal information, as well as
providing individuals with a right to access and correct their own personal records.

The Privacy Amendment (Private Sector) Act 2000 (Cth) was passed by the House of Representatives and the
Senate in early December 2000. It comes into effect on 21 December 2001. The Act amends the Privacy Act
1988 to extend coverage to the private sector in Australia.

The Act introduces a ‘light touch’ legislative regime based around National Privacy Principles. However, there
are a number of limitations in the Act, and therefore coverage does not extend to the handling of all personal
information by the private sector. For example, the Act does not apply to:

- small businesses with a turnover of less than $3 million
  (although this exception does not apply to health services)
- employee records (including health information stored on those records)
- media
- collection, use and disclosure of information by political parties.

The small business exemption does not extend to providers of health services and therefore all health service
providers are covered by the Act, except in relation to their own employee records. Notwithstanding this, a

25 Panacea or Placebo? Linked Electronic Health Records and Improvements in Health Outcomes, recommendations 3 - 5 at pages 4 - 5.
‘light touch’ approach to the protection of health information is inadequate for a number of reasons. Some of the main concerns with the adequacy of the amendments are:

- that the amended Act does not deal with the increased blurring of private and public sector organisations, and in the health field this is a significant issue
- it provides a complex framework for exemptions making it difficult for individuals to form a clear idea of the privacy standards they can expect from some key areas of private sector business, for example small businesses are excluded from the Bill, and it is difficult for individuals to tell which organisations are covered.

This could be so even where health information is concerned, if the business in question is not a health service provider as defined by the legislation and has an annual turnover of less than $3 million.

The exclusion for employment records is also a problem, and may mean that employers’ handling of staff health records is not covered in some situations.

The federal Privacy Commissioner, in consultation with health consumers and professionals, has developed draft health guidelines. In general, the draft guidelines are far more comprehensive and would greatly improve the protection offered by the amended Act. However, the guidelines are advisory only and are not legally binding. They also cannot correct the deficiencies arising from legislative exemptions and the inadequate and potentially inconsistent complaint mechanism provided by the Act.

Conclusions and recommendations

It is clear from the evidence to this Enquiry that once a person’s status becomes known, whether by voluntarily disclosure, inappropriate requirements for disclosure, or as a result of breaches of confidentiality, discrimination often follows. Adequate and effective privacy legislation is of vital importance in reducing discrimination against people with hepatitis C, particularly in employment and health care settings.

Recommendations in relation to compliance with privacy legislation in health care, employment and educational settings have been made in Chapter 2, sections 2.3, 2.4, and 2.8.

The Enquiry recommends that:

78. The NSW Government enact specific legislation dealing with privacy of health information as recommended by the NSW Ministerial Advisory Committee on Privacy and Health Information.

79. The NSW Government ensure that the NSW Privacy Commissioner is adequately resourced to fulfil the expanded role.
Conclusions
The evidence to this Enquiry clearly demonstrates that hepatitis C is a highly stigmatised condition and discrimination against people with hepatitis C is rife. Such discrimination is often the result of an inadequate understanding of the transmissibility of hepatitis C, and consequently driven by irrational fears about hepatitis C infection. However, perhaps more powerful than ignorance about hepatitis C transmission, is that hepatitis C infection is inextricably linked to illicit drug use, which is highly stigmatised behaviour.

Evidence to this Enquiry makes it abundantly clear that discrimination against people with hepatitis C is often motivated by stereotyped responses towards people on the basis of past, current or assumed injecting drug use. The mere fact that a person has a history of injecting drug use or is currently using drugs should not be arbitrarily used as a rationale for denying people access to services or employment or for treating them in any other discriminatory manner.

Precisely because of the confounding of hepatitis C with injecting drug use, addressing discrimination on the basis of drug use must be an integral part of responding effectively to hepatitis C related discrimination. When we speak of hepatitis C related discrimination, it must be understood that this necessarily includes discrimination associated with illicit drug use, although, as we have noted, not all injected drugs are illicit.

Information about a person's hepatitis C status is highly sensitive. It is common for people with hepatitis C to live with constant fear about their hepatitis C status becoming known. There is little wonder that this is the case given the adverse consequences that so often flow when a person discloses their hepatitis C status or where breaches of confidentiality occur. The right to privacy and confidentiality has been described as the first line of defence against discrimination: the successful defending of these rights usually offers some protection against a variety of forms of discrimination. Ensuring that people's rights to confidentiality and privacy are protected is of critical importance. Nonetheless, in and of itself, protecting people's privacy and confidentiality does not go to the heart of the problem — the stigma associated with hepatitis C infection and injecting drug use.

Hepatitis C related discrimination takes many forms and occurs in many areas of public life. The Enquiry has heard a wide range of examples of discrimination experienced by people with hepatitis C such as people being rejected by family and friends, ostracised in workplaces and communities, denied life insurance, and terminated from employment. Family and friends have been denied the right to view the body of a person known or assumed to be hepatitis C positive.

Health care settings were the most widely reported context for hepatitis C related discrimination. It is apparent from the evidence that hepatitis C related discrimination in health care settings is widespread. In its most overt form, people are refused health care services and treatment on the basis of their hepatitis C status or past, current or assumed drug use. In its more subtle forms, people are made to feel that they have less entitlement to quality health care, undermining their sense of self worth.

Second only to discrimination in health care settings is discrimination in employment. Discrimination in employment is extensive. The evidence highlights that selection and recruitment practices deter people with hepatitis C from seeking employment, and loss of employment and harassment in employment are commonplace. So too, impediments to the effective delivery of health care and health promotion services in custodial settings have significant and detrimental consequences for the health of all prisoners, including many inmates with hepatitis C in the NSW correctional system. In turn this impacts upon the families of prisoners and others in the community to whom they return, many after serving relatively short sentences. The demonstrably high risk of hepatitis C infection within the correctional system is unacceptable and needs to be urgently addressed.

Discrimination often has a profound impact on the lives of people with hepatitis C, including damaging health, financial, social and emotional consequences both for people living with hepatitis C and for the community. The experience of discrimination acts a deterrent to people accessing the health system, with all the consequences this brings, for the health of people with hepatitis C, their families and the community. The fear of stigma and discrimination can lead people who believe they might already have contracted hepatitis C, to be reluctant to seek testing for hepatitis C. Not seeking out testing limits the possibility of either considering appropriate treatment options or taking actions to manage their health effectively. It also means that people with hepatitis C are less likely to be in contact with health and support services and are harder to reach with information about hepatitis C prevention. Discrimination in the workplace leads to

people being sacked or forced to leave their jobs. Discrimination in selection and recruitment practices act as a significant deterrent to people with hepatitis C applying for work.

The lived experience of hepatitis C discrimination is not easily understood solely from the perspective of discrimination as defined by anti-discrimination legislation. Many of the issues raised by people during the course of the Enquiry may not necessarily be resolved by resort to anti-discrimination complaint systems. It is also clear that the evidence does raise examples of discrimination which may be actionable under anti-discrimination legislation, yet few complaints are made under federal or NSW anti-discrimination legislation. It is apparent that there are real limits to the capacity of individual complaint mechanisms to adequately address hepatitis C related discrimination. This is due, in part, to the barriers people face in accessing anti-discrimination and other complaint mechanisms. Nonetheless, the significance of anti-discrimination legislation lies not only in the remedies that the law provides where a person has been discriminated against. By making hepatitis C discrimination, harassment and victimisation in public life unlawful, we collectively make a statement about how we expect everyone to be treated - with dignity and respect. These principles of equality and non-discrimination are enshrined in the legislation, providing a framework for reducing and eliminating hepatitis C discrimination.

It is evident that hepatitis C related discrimination requires a multi-faceted approach. Organisational infrastructure needs to provide clear policies and support practices which protects people’s privacy and confidentiality, and ensures the implementation of standard infection control. Education initiatives are vital to reducing the incidence of discrimination by enabling people to understand how hepatitis C is transmitted and the means by which the risks of transmission can be reduced. It also encourages people to challenge the validity of moral judgments about illicit drug use and stereotyping of people who have injected or do inject drugs. The people affected by hepatitis C related discrimination need to be better informed about their rights and supported to utilise complaint mechanisms. Anti-discrimination legislation needs to be strengthened to ensure systemic discrimination is not solely reliant upon individuals lodging complaints.

The association of ‘disease’ with stigmatised behaviour has often lead to discrimination. Societies have shown a distressing record of treating people with particular diseases as outcasts and denying them fundamental human dignity. Take for example the appearance of certain sexually transmitted infections in the fifteenth century. Such response have been more recently exposed in reactions to the appearance of HIV/AIDS in the 1980’s.

The critical role that protection of human rights has to play in responding to public health challenges has burgeoned in the wake of the global HIV/AIDS pandemic. Such discourse has recently had a significant influence on policy, legislative and service responses to HIV/AIDS, both internationally and domestically.

The realisation of human rights was indeed critical to the survival and dignity of people living with HIV, but it was also a critical component of reducing the risk of acquiring infection among those whose vulnerability was determined by inequalities and stigma associated with a host of attributes including race, gender, social and economic status, sexuality and behaviours.

The parallels between earlier diseases, HIV/AIDS and hepatitis C are clearly evident. Protection of the human rights of people with hepatitis C, and those most at risk of infection, particularly people who inject illicit drugs, is critical to an effective response to hepatitis C.

It is also the least we can expect if we wish to be regarded as a decent and compassionate society.

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2 This historical context is considered in more detail in the Forward to this report.

Appendices
Appendix A
Members of the Enquiry

The Enquiry was chaired by Mr Chris Puplick AM, assisted by members of the Statutory Board, Ms Suzanne Jamieson and Father Hugh Murray OAM.

Mr Chris Puplick is the President of the NSW Anti-Discrimination Board and NSW Privacy Commissioner. He was appointed President of the ADB in 1994.

Ms Suzanne Jamieson is a Senior Lecturer in Work and Organisational Studies at the University of Sydney. She has recently completed a doctorate in Women and Occupational Health Safety, and has done extensive research in gender and discrimination issues in the workplace.

Father Hugh Murray is a Catholic priest of the Vincentian Order. He has spent most of his life working in education. Before retirement, Father Murray spent several years as the Catholic Chaplain for people with HIV in the City of Sydney.

Members of the Enquiry Steering Committee
Professor Bob Batey
Director, Gastroenterology Unit, John Hunter Hospital

Mr Jack Wallace
Executive Officer, Australian Hepatitis Council

Mr Stuart Loveday
Executive Officer, Hepatitis C Council of NSW

Professor Sue Kippax
Director, National Centre in HIV Social Research

Ms Maureen Steele
Community Advocacy Coordinator, NSW Users and AIDS Association

Ms Annie Madden
Executive Officer, Australian Intravenous League

Dr Ingrid van Beek
Director, Kirketon Road Centre

Project Officer
Ms Julia Cabassi, a Legal Officer of the ADB, was the project officer responsible for managing the Enquiry. Ms Cabassi is the principal author of the report.
Appendix B
Media coverage

The conduct of the Enquiry has provided an important opportunity to raise community awareness about hepatitis C related discrimination, and to promote the role of the ADB and compliance with anti-discrimination legislation. The Enquiry received considerable media attention, centred around the conduct of the public hearings in Sydney and regional centres. The coverage was generally well informed and provided an important opportunity to raise hepatitis C related discrimination issues in regional newspapers and on regional radio.

Radio interviews
Many of the radio stations recorded two interviews, an introductory piece about the Enquiry hearing interview, and a round up of the day’s events.

Radio 2GN, Goulburn
ABC 973, Wollongong
ABC Radio Newcastle
Radio 2HD
Radio 2NX
Radio 2NO FM
Radio 2GN News, Dubbo
ABC Radio Central West, Dubbo
Radio 2GN
Radio 2LM, Lismore

Press coverage
Goulburn Post, pre and post Enquiry hearings coverage
Illawarra Mercury
Newcastle Herald
Dubbo Daily Liberal

Television coverage
The 7.30 Report filmed at the Wollongong hearing and interviewed the President about the Enquiry. The story also examined the high risk of hepatitis C transmission in custodial settings, including interviews with prison activists and the NSW Department of Corrective Services. The report went to air on 14 June 2001. Prime Television filmed at the Wollongong hearing, and their package was broadcast through their rural network across the State. Prime Television also filmed at the Newcastle hearing.
Appendix C
Oral submissions

Enquiry launch
— 15 March 2001
Professor Bob Batey
John Hunter Hospital, University of Newcastle
Chair of the Hepatitis C Sub-Committee of the Australian National Council on AIDS, Hepatitis C and Related Diseases
Mr Stuart Loveday
Executive Officer, Hepatitis C Council of NSW
Mr Paul Harvey
Special Projects Officer, Hepatitis C Council of NSW
Ms Maureen Steel
Community Advocacy Coordinator, NSW Users and AIDS Association

Goulburn Public Hearing
— 8 May 2001
Dr Michael Levy
Director of Population Health, Corrections Health Service
Ms Alita O’Meara
Public Health Nurse, Goulburn and Berrima Correctional Centre
Ms Jenni Somers
Sexual Health Counsellor, Moruya Community Health Centre
Ms Sharon Medway
Indigenous Sexual Health Worker, Southern Area Health Service
Ms Angela Trevaskis
Sexual Health Counsellor, Queanbeyan Community Health Centre
Ms Lorraine Dubois
Acting Sexual Health/HCV Coordinator, Southern Area Health Service
Mr Brian Callahan
Area Methadone Service Manager, Southern Area Health Service (Drug and Alcohol)

Wollongong Public Hearing
— 9 May 2001
Mr Richard Carbury
Unit Manager, Dennison Street Private Methadone Clinic
Ms Cheryl Wifton
Service Manager, Contact Drug and Alcohol Service
Ms Jane Anderson
Drug and Alcohol Counsellor, Contact Drug and Alcohol Service

Newcastle Public Hearing
— 15 May 2001
Ms Marilyn Bliss
AIDS and Infectious Diseases Coordinator, Hunter Area Health Service
Mr Michael Pope
HCV Project Officer, Hunter Area Health Service
Ms Tracey Jones
Clinical Nurse Consultant, John Hunter Hospital
Ms Gabrielle Murphy
HCV Social Worker, John Hunter Hospital
Mr Keith King
Needle and Syringe Program Coordinator, Hunter Area Health Service
Mr Ken Zulumovski
Sexual Health Worker, Awabakal Aboriginal Medical Service
Ms Trish Tanner
Acting Nurse Unit Manager, Newcastle Methadone Unit

Dubbo Public Hearing
— 16 May 2001
Ms Maggie Westman
Acting AIDS Coordinator, Macquarie Area Health Service
Ms Fiona Baker
Nurse Unit Manager, Methadone Management Program, Macquarie Area Health Service
Ms Maria Walsh
Case Worker, Drug and Alcohol Unit, Macquarie Area Health Service
Mr David Ward
Solicitor, Community Legal Service for Western NSW
Mr David Kelly
CEO, Wellington Aboriginal Corporations Health Service
Ms Bedelia Skinner
Needle and Syringe Program Coordinator, Macquarie Area Health Service
Mr Steve Gibson
Aboriginal Health Coordinator, Macquarie Area Health Service
Lismore Public Hearing  
— Wednesday 23 May

Ms Wendi Evans  
AIDS and Infectious Diseases Coordinator,  
Northern Rivers Area Health Service

Mr Scott Russell  
HCV Project Officer, Northern Rivers Area Health Service

Ms Marilyn Marks  
HIV, HCV and Sexual Health Educator,  
Grafton Community Health Centre

Mr Christian Gruft  
Needle and Syringe Program Coordinator,  
Western Cluster Primary and Extended Care Services (PECS),  
Northern Rivers Area Health Service

Ms Deb Woodbridge  
HCV Study Project Officer,  
Southern Cross Institute of Health Research

Ms Bernadette Monaghan  
HCV Study Project Officer,  
Southern Cross Institute of Health Research

Mr Robert Monaghan  
Sexual Health Educator, Bulgarr Ngaru Aboriginal Medical Service

Ms Yana Van der Jagt  
HCV and Needle and Syringe Program Coordinator,  
Mid North Coast Area Health Service

Ms Roslyn Hawkins  
Clinical Nurse Consultant, Sexual Health Clinic,  
Northern Rivers Area Health Service

The Hon. Dr Brian Patrick Victor Pezzutti  
Member of Legislative Council (NSW)

Sydney Public Hearings  
— 2 and 3 August 2001

Dr Ingrid van Beek  
Director, Kirketon Road Centre

Ms Annie Madden  
Executive Officer, Australian Intravenous League

Dr Alex Wodak  
Director, St Vincent's Hospital Drug and Alcohol Service

Mr David Mico  
Senior Policy Manager,  
Investment & Financial Services Association

Mr Brian Sussman  
General Manager,  
Gerling Global Life Reinsurance Company of Australia Pty Limited

Dr Patrick O'Brien  
Development Manager, GeneralCologne Life Re Australia Ltd

Mr Gary Gahan  
Coordinator Hepatitis C Services Network (HepNet),  
North Sydney Area Health Service

Ms Sue Mason  
Clinical Nurse Consultant, HCV, Royal Prince Alfred Hospital,  
Central Sydney Area Health Service

Ms Sinead Shells  
Clinical Nurse Consultant, HCV, Royal Prince Alfred Hospital,  
Central Sydney Area Health Service

Mr Brad Freeburn  
Drug and Alcohol Educator,  
Redfern Aboriginal Medical Service

Dr John Daniels  
Redfern Aboriginal Medical Service

Professor Michael Kidd  
Head of Department,  
Department of General Practice, University of Sydney

Ms Levinia Crooks  
Australian Society for HIV Medicine

Dr Gillian Deakin  
General Practitioner

Mr Stuart Loveday  
Executive Officer, Hepatitis C Council of NSW

Ms Margaret Gearin  
President, Hepatitis C Council of NSW

Ms Maureen Steele  
Community Advocacy Coordinator,  
NSW Users and AIDS Association

Mr Stephen Wye  
Editor, Users News, NSW Users and AIDS Association

Private hearings

The Enquiry also conducted private sessions at each of the regional locations outlined above and held private hearings at:

- Hepatitis C Council of NSW — 29 May 2001
- Kirketon Road Centre — 5 June 2001
- Mulawa Women’s Correctional Facility — 26 July 2001
- Joint Assessment Review Team Offices —  

The Enquiry heard evidence from 15 health workers and 45 individuals in these private sessions.
Appendix D
Written Submissions

Ageing and Disability Department of NSW
AIDS Council of NSW Inc
Australian Dental Association (NSW Branch)
Australian Health Ethics Committee of the National Health and Medical Research Council
Australian Hepatitis Council
Australian National Council on AIDS, HCV and Related Diseases, HCV Committee
Australian Research Centre in Sex Health and Society
Central Sydney Area Health Service
Combined Community Legal Centres Group (NSW)
Corrections Health Service
Council of Social Service of New South Wales
Crookwell District Hospital
Darwin Community Legal Service
Department of Juvenile Justice
Dr W. J. Kingswell
Dr A. R. MacQueen
DUNES Inc
Far West Area Health Service
Health Care Complaints Commission
Hepatitis C Council of NSW
Hepatitis C Council of SA
Hepatitis C Council of WA
Hepatitis C Helpline (Victoria)
HIV/AIDS Legal Centre Inc
Investment and Financial Service Association
Mid North Coast Area Health Service
Multicultural HIV/AIDS Service
National Drug and Alcohol Research Centre
New England Area Health Service
Northern River Area Health Service
Northern River Community Legal Centre
Northern Sydney Area Health Service
NSW Department of Corrective Services
NSW Health Department
NSW Users and AIDS Association
Office of the Director of Equal Opportunity in Public Employment
Options Employment and Training Service
Phoebe House Inc
Prison Aware
Positive Justice Centre
Professor Sandy Gifford
Royal Australasian College of Physicians
South East Health Area Health Service
Southern Area Health Service
Sussex Street Community Law Service (WA)
Sex Workers Outreach Program
TRAIDS
Waikerie Medical Centre

We also received 62 written submissions from individuals.
Appendix E
An Epidemic of Difference: A Social Analysis of Hepatitis C-related Discrimination

NATIONAL CENTRE IN HIV SOCIAL RESEARCH

A. Introduction

B. Background to the hepatitis C epidemic in Australia

C. Discrimination and stigma
   C1. Social identity
   C2. Fear of contagion and ‘userphobia’

D. Method
   D1. Submissions from the health care sector

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

F. Themes of stigma and practice of discrimination
   F1. Disclosure
   F2. The ‘innocent’ and ‘guilty’ victims of hepatitis C
   F3. Discrimination of hepatitis C-related health care workers
   F4. The tools of harm reduction: resistance to drug-related health services
   F5. Access to hepatitis C and other health services
   F6. Confidentiality
   F7. Poor medical treatment and exclusion from health services

G. Affective responses to hepatitis C-related discrimination
   G1. Learned helplessness

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

I. Conclusion

J. References
A. Introduction

In November 2000, the President of the Anti-Discrimination Board of New South Wales (ADB), Mr Chris Puplick, announced a statewide Enquiry into hepatitis C-related discrimination. The Enquiry was launched in Sydney on March 15th 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 (Done 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’1. 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 programs 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 conceptualisation of discrimination has been critiqued for its assumption that attitudes and behaviour are always consistent (Merton 1970). Another approach to discrimination looks beyond personal rationalisations and motivations to social

1Courtesy of Dr Erica Southgate.
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 stigmatisate individuals or groups of people who display difference from social norms and who identify with or enact behaviours that hegemonic groups consider deviant.

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 marginalising those people who exhibit particular traits (Malcolm et al. 1998; Gilmore et al. 1994). Stigmatisation involves the labelling 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 stigmatising 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.

C1. 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 victimisation 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 categorise 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 stigmatising 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 labelled 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 labelled 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 unrealised 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 characterised 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 stigmatising, 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…Stigmatisation 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.’

(Triner et al. 1989, p. 391)

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 (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 programs. 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 injecting drug 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).

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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 injecting drug users, 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 organisations, 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 organisations 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 programs, 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 hepatitides. 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 GPs.

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 GPs 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 program 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 GPs 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 medicinally acquired hepatitis C implied that people are rational beings and must be held accountable for their own behaviour. Therefore, those with medicinally 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 programs (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 programs, 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 programs, 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 programs and methadone maintenance treatment. In some regions, needle and syringe vending machines were vandalised. 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 programs because they are seen as ‘sending the wrong message’. Another worker believes that the Aboriginal Medical Service resists needle and syringe programs 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 labelling 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 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 recognise 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, patronising, 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
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 demoralised…[my wife’s] constant distress at my inabilty…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 transmission as well as hepatitis C-related discrimination. ‘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 labelling them as ‘sick’ and infectious, is deployed as a method of preserving the physical health of communities against the complications represented by the disease.

When 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 categorisation 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 characterised as having prioritised 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 explains 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.

J. References


Appendix F
Extracts of Legislation

This Appendix provides extracts of legislation referred to in this report.

Anti-Discrimination Act
1977 (NSW)

4 Definitions

disability means:…
(b) the presence in a person’s body of organisms causing or capable of causing disease or illness…

services includes:
(a) services relating to banking, insurance and the provision of grants, loans, credit or finance,
(b) services relating to entertainment, recreation or refreshment,
(c) services relating to transport or travel,
(d) services of any profession or trade,
(e) services provided by a council or public authority,
(f) services consisting of access to, and the use of any facilities in, any place or vehicle that the public or a section of the public is entitled or allowed to enter or use, for payment or not.

49A Disability includes past, future and presumed disability

A reference in this Part to a person’s disability is a reference to a disability:
(a) that a person has, or
(b) that a person is thought to have (whether or not the person in fact has the disability), or
(c) that a person had in the past, or is thought to have had in the past (whether or not the person in fact had the disability), or
(d) that a person will have in the future, or that it is thought a person will have in the future (whether or not the person in fact will have the disability).

49B What constitutes discrimination on the ground of disability

(1) A person (the perpetrator) discriminates against another person (the aggrieved person) on the ground of disability if, on the ground of the aggrieved person’s disability or the disability of a relative or associate of the aggrieved person, the perpetrator:
(a) treats the aggrieved person less favourably than in the same circumstances, or in circumstances which are not materially different, the perpetrator treats or would treat a person who does not have that disability or who does not have such a relative or associate who has that disability; or
(b) requires the aggrieved person to comply with a requirement or condition with which a substantially higher proportion of persons who do not have that disability, or who do not have such a relative or associate who has that disability, comply or are able to comply, being a requirement which is not reasonable having regard to the circumstances of the case and with which the aggrieved person does not or is not able to comply.
(2) For the purposes of subsection (1) (a), something is done on the ground of a person’s disability if it is done on the ground of the person’s disability, a characteristic that appertains generally to persons who have that disability or a characteristic that is generally imputed to persons who have that disability.
(3) For the purposes of, but without limiting, this section, the fact that a person has a disability of or relating to vision, hearing or mobility has, or may be accompanied by, a dog which assists the person in respect of that disability, is taken to be a characteristic that appertains generally to persons who have that disability, but nothing in this Act affects the liability of any such person for any injury, loss or damage caused by the dog.
(4) A reference in this section to persons who have a disability (“the particular disability”) is a reference to persons who have the particular disability or who have a disability that is substantially the same as the particular disability.

49C What constitutes unjustifiable hardship

In determining what constitutes unjustifiable hardship for the purposes of this Part, all relevant circumstances of the particular case are to be taken into account including:
(a) the nature of the benefit or detriment likely to accrue or be suffered by any persons concerned; and
(b) the effect of the disability of a person concerned; and
(c) the financial circumstances and the estimated amount of expenditure required to be made by the person claiming unjustifiable hardship.

49D Discrimination against applicants and employees

(1) It is unlawful for an employer to discriminate against a person on the ground of disability:
(a) in the arrangements the employer makes for the
(2) It is unlawful for an employer to discriminate against an employee on the ground of disability:
   (a) in the terms or conditions of employment which the employer affords the employee, or
   (b) by denying the employee access, or limiting the employee’s access, to opportunities for promotion, transfer or training, or to any other benefits associated with employment, or
   (c) by dismissing the employee, or
   (d) by subjecting the employee to any other detriment.

(3) Subsections (1) and (2) do not apply to employment:
   (a) for the purposes of a private household, or
   (b) where the number of persons employed by the employer, disregarding any persons employed within the employer’s private household, does not exceed 5, or
   (c) by a private educational authority.

(4) Nothing in subsection (1) (b) or (2) (c) renders unlawful discrimination by an employer against a person on the ground of the person’s disability if taking into account the person’s past training, qualifications and experience relevant to the particular employment and, if the person is already employed by the employer, the person’s performance as an employee, and all other relevant factors that it is reasonable to take into account, the person because of his or her disability:
   (a) would be unable to carry out the inherent requirements of the particular employment, or
   (b) would, in order to carry out those requirements, require services or facilities that are not required by persons without that disability and the provision of which would impose an unjustifiable hardship on the employer.

(5) For the purposes of subsection (3) (b), a corporation is taken to be the employer of the employees of any other corporation which, with respect to the firstmentioned corporation, is taken to be a related corporation within the meaning of the Corporations Law.

In relation to discrimination in employment, see also sections 49E–49K, covering discrimination against commission agents, contract workers, in partnerships, by local government councillors and industrial organisations, qualifying bodies and employment agencies.

49L Education

(1) It is unlawful for an educational authority to discriminate against a person on the ground of disability:
   (a) by refusing or failing to accept his or her application for admission as student; or
   (b) in the terms on which it is prepared to admit him or her as a student.

(2) It is unlawful for an educational authority to discriminate against a student on the ground of disability:
   (a) by denying him or her access, or limiting his or her access, to any benefit provided by the educational authority; or
   (b) by expelling him or her; or
   (c) by subjecting him or her to any other detriment.

(3) Nothing in this section applies to or in respect of:
   (a) a private educational authority; or
   (b) a refusal or failure to accept a person’s application for admission as a student by an educational authority where the educational authority administers a school, college, university or other institution which is conducted solely for students who have a disability which is not the same as that of the applicant.

(4) Nothing in subsection (1) (a) or (2) (b) renders it unlawful to discriminate against a person on the ground of disability where, because of the person’s disability, the person requires services or facilities that are not required by students who do not have a disability and the provision of which would impose unjustifiable hardship on the educational authority.

(5) Nothing in subsection (2) (a) renders it unlawful to discriminate against a person on the ground of disability where, because of the person’s disability, the person requires the benefit to be provided in a special manner and the benefit cannot without unjustifiable hardship be so provided by the educational authority.

49M Provision of goods and services

(1) It is unlawful for a person who provides, for payment or not, goods or services to discriminate against a person on the ground of disability:
   (a) by refusing to provide the person with those goods or services; or
   (b) in the terms on which he or she provides the person with those goods or services.

(2) Nothing in this section renders it unlawful to discriminate against a person on the ground of the person’s disability if the provision of the goods and services would impose unjustifiable hardship on the person who provides the goods and services.

49N Accommodation

(1) It is unlawful for a person, whether as principal or agent, to discriminate against a person on the ground of disability:
   (a) by refusing the person’s application for accommodation, or
   (b) in the terms on which the person is offered accommodation, or
   (c) by deferring the person’s application for accommodation or according the person a lower order of precedence in any list of applicants for that accommodation.
(2) It is unlawful for a person, whether as principal or agent, to discriminate against a person on the ground of disability:
   (a) by denying the person access, or limiting the person’s access, to any benefit associated with accommodation occupied by the person, or
   (b) by evicting the person, or
   (c) by subjecting the person to any other detriment.

(3) Nothing in this section applies to or in respect of the provision of accommodation in premises if:
   (a) the person who provides or proposes to provide the accommodation or a near relative of that person resides, and intends to continue to reside, on those premises, and
   (b) the accommodation provided in those premises is for no more than 6 persons.

(4) Nothing in this section applies to the provision of accommodation in premises where special services or facilities would be required by the person with a disability and the provision of such special services or facilities would impose unjustifiable hardship on the person providing or proposing to provide the accommodation whether as principal or agent.

(5) Nothing in this section applies to the provision of accommodation to persons who have a particular disability by a charitable body or other body that does not distribute its profits to members.

(6) Nothing in subsection (2) (a) renders it unlawful to discriminate against a person on the ground of disability where, because of the person’s disability, the person requires the benefit to be provided in a special manner and the benefit cannot without unjustifiable hardship be so provided by the person who provides the accommodation.

49Q Superannuation, insurance
Nothing in this Part renders unlawful discrimination against a person on the ground of disability in the terms or conditions appertaining to a superannuation or provident fund or scheme or with respect to the terms on which an annuity, a life assurance policy, an accident or insurance policy or other policy of insurance is offered or may be obtained, where:
   (a) the terms or conditions:
      (i) are based upon actuarial or statistical data on which it is reasonable to rely, and
      (ii) are reasonable having regard to the data and any other relevant factors, or
   (b) in a case where no such actuarial or statistical data is available and cannot reasonably be obtained—the terms or conditions are reasonable having regard to any other relevant factors, and the source on which the data referred to in paragraph (a) is based is disclosed to the Tribunal, where the Tribunal so requires, and any other relevant factors to which regard has been had as referred to in paragraph (a) or (b) are disclosed to the Tribunal, where the Tribunal so requires.

50 Victimisation
(1) It is unlawful for a person (the discriminator) to subject another person (the person victimised) to any detriment in any circumstances on the ground that the person victimised has:
   (a) brought proceedings against the discriminator or any other person under this Act,
   (b) given evidence or information in connection with proceedings brought by any person against the discriminator or any other person under this Act,
   (c) alleged that the discriminator or any other person has committed an act which, whether or not the allegation so states, would amount to a contravention of this Act, or
   (d) otherwise done anything under or by reference to this Act in relation to the discriminator or any other person, or by reason that the discriminator knows that the person victimised intends to do any of those things, or suspects that the person victimised has done, or intends to do, any of them.

(2) Subsection (1) does not apply to the subjecting of a person to a detriment by reason of an allegation made by the person if the allegation was false and not made in good faith.

54 Acts done under statutory authority
(1) Nothing in this Act renders unlawful anything done by a person if it was necessary for the person to do it in order to comply with a requirement of:
   (a) any other Act, whether passed before or after this Act,
   (b) any regulation, ordinance, by-law, rule or other instrument made under any such other Act,
   (c) an order of the Tribunal,
   (d) an order of any court, not including an order or award of a court or tribunal having power to fix minimum wages and other terms and conditions of employment, or
   (e) (Repealed)

(2) (Repealed)

(3) Except as provided in this section, this Act has effect notwithstanding anything contained in:
   (a) the Co-operation Act 1923,
   (b) the Financial Institutions (New South Wales) Act 1992,
   (c) the Friendly Societies (NSW) Code or the Friendly Societies (NSW) Regulations,
   (c1) the Co-operatives Act 1992,
   (d), (e) (Repealed)
   (f) the Registered Clubs Act 1976,
or any instrument of whatever nature made or approved thereunder.
4 Interpretations

**disability**, in relation to a person, means:…

(c) the presence in the body of organisms causing disease or illness; or

(d) the presence in the body of organisms capable of causing disease or illness; or…

**services** includes:

(a) services relating to banking, insurance, superannuation and the provision of grants, loans, credit or finance; or

(b) services relating to entertainment, recreation or refreshment; or

(c) services relating to transport or travel; or

(d) services relating to telecommunications; or

(e) services of the kind provided by the members of any profession or trade; or

(f) services of the kind provided by a government, a government authority or a local government body.

5 Disability discrimination

(1) For the purposes of this Act, a person (**discriminator**) discriminates against another person (**aggrieved person**) on the ground of a disability of the aggrieved person if, because of the aggrieved person’s disability, the discriminator treats or proposes to treat the aggrieved person less favourably than, in circumstances that are the same or are not materially different, the discriminator treats or would treat a person without the disability.

(2) For the purposes of subsection (1), circumstances in which a person treats or would treat another person with a disability are not materially different because of the fact that different accommodation or services may be required by the person with a disability.

11 Unjustifiable hardship

For the purposes of this Act, in determining what constitutes unjustifiable hardship, all relevant circumstances of the particular case are to be taken into account including:

(a) the nature of the benefit or detriment likely to accrue or be suffered by any persons concerned; and

(b) the effect of the disability of a person concerned; and

(c) the financial circumstances and the estimated amount of expenditure required to be made by the person claiming unjustifiable hardship; and

(d) in the case of the provision of services, or the making available of facilities — an action plan given to the Commission under section 64.

15 Discrimination in employment

(1) It is unlawful for an employer or a person acting or purporting to act on behalf of an employer to discriminate against a person on the ground of the other person’s disability or a disability of any of that other person’s associates:

(a) in the arrangements made for the purpose of determining who should be offered employment; or

(b) in determining who should be offered employment; or

(c) in the terms or conditions on which employment is offered.

(2) It is unlawful for an employer or a person acting or purporting to act on behalf of an employer to discriminate against an employee on the ground of the employee’s disability or a disability of any of that employee’s associates:

(a) in the terms or conditions of employment that the employer affords the employee; or

(b) by denying the employee access, or limiting the employee’s access, to opportunities for promotion, transfer or training, or to any other benefits associated with employment; or

(c) by dismissing the employee; or

(d) by subjecting the employee to any other detriment.

(3) Neither paragraph (1)(a) nor (b) renders it unlawful for a person to discriminate against another person, on the ground of the other person’s disability, in connection with employment to perform domestic duties on the premises on which the first-mentioned person resides.

(4) Neither paragraph (1)(b) nor (2)(c) renders unlawful discrimination by an employer against a person on the ground of the person’s disability, if taking into account the person’s past training, qualifications and experience relevant to the particular employment and, if the person is already employed by the employer, the person’s performance as an employee, and all other relevant factors that it is reasonable to take into account, the person because of his or her disability:

(a) would be unable to carry out the inherent requirements of the particular employment; or

(b) would, in order to carry out those requirements, require services or facilities that are not required by persons without the disability and the provision of which would impose an unjustifiable hardship on the employer.

In relation to discrimination in employment, also see Sections 16–21, covering discrimination against commission agents, contract workers, in partnerships, by registered organisations under Workplace Relations Act, qualifying bodies and employment agencies.
22 Education

(1) It is unlawful for an educational authority to discriminate against a person on the ground of the person's disability or a disability of any of the other person's associates:

(a) by refusing or failing to accept the person's application for admission as a student; or
(b) in the terms or conditions on which it is prepared to admit the person as a student.

(2) It is unlawful for an educational authority to discriminate against a student on the ground of the student's disability or a disability of any of the student's associates:

(a) by denying the student access, or limiting the student's access, to any benefit provided by the educational authority; or
(b) by expelling the student; or
(c) by subjecting the student to any other detriment.

(3) This section does not render it unlawful to discriminate against a person on the ground of the person's disability in respect of admission to an educational institution established wholly or primarily for students who have a particular disability where the person does not have that particular disability.

(4) This section does not render it unlawful to refuse or fail to accept a person's application for admission as a student where the person, if admitted as a student by the educational authority, would require services or facilities that are not required by students who do not have a disability and the provision of which would impose unjustifiable hardship on the educational authority.

24 Goods, services and facilities

(1) It is unlawful for a person who, whether for payment or not, provides goods or services, or makes facilities available, to discriminate against another person on the ground of the other person's disability or a disability of any of that other person's associates:

(a) by refusing to provide the other person with those goods or services or to make those facilities available to the other person; or
(b) in the terms or conditions on which the first-mentioned person provides the other person with those goods or services or makes those facilities available to the other person; or
(c) in the manner in which the first-mentioned person provides the other person with those goods or services or makes those facilities available to the other person.

(2) This section does not render it unlawful to refuse or fail to accept a person's application for admission as a student at an educational institution where the person, if admitted as a student by the educational authority, would require services or facilities that are not required by students who do not have a disability and the provision of which would impose unjustifiable hardship on the educational authority.

25 Accommodation

(1) It is unlawful for a person, whether as principal or agent, to discriminate against another person on the ground of the other person's disability or a disability of any of that other person's associates:

(a) by refusing the other person's application for accommodation; or
(b) in the terms or conditions on which the accommodation is offered to the other person; or
(c) by deferring the other person's application for accommodation or according to the other person a lower order of precedence in any list of applicants for that accommodation.

(2) It is unlawful for a person, whether as principal or agent, to discriminate against another person on the ground of the other person's disability or a disability of any of the other person's associates:

(a) by denying the other person access, or limiting the other person's access, to any benefit associated with accommodation occupied by the other person; or
(b) by evicting the other person from accommodation occupied by the other person; or
(c) by subjecting the other person to any other detriment in relation to accommodation occupied by the other person; or
(d) by refusing to permit the other person to make reasonable alterations to accommodation occupied by that person if:

(i) that person has undertaken to restore the accommodation to its condition before alteration on leaving the accommodation; and
(ii) in all the circumstances it is likely that the person will perform the undertaking; and
(iii) in all the circumstances, the action required to restore the accommodation to its condition before alteration is reasonably practicable; and
(iv) the alteration does not involve alteration of the premises of any other occupier; and
(v) the alteration is at that other person's own expense.

(3) This section does not apply to or in respect of:

(a) the provision of accommodation in premises if:

(i) the person who provides or proposes to provide the accommodation or a near relative of that person resides, and intends to continue to reside on those premises; and
(ii) the accommodation provided in those premises is for no more than 3 persons other than a person referred to in subparagraph (a)(i) or near relatives of such a person; or

(b) the accommodation is provided by a charitable or other voluntary body solely for persons who have a particular disability and the person discriminated against does not have that particular disability; or
(c) the provision of accommodation in premises where special services or facilities would be required by the person with a disability and the provision of such special services or facilities would impose unjustifiable hardship on the person providing or proposing to provide the accommodation whether as principal or agent.

46 Superannuation and insurance

(1) This Part does not render it unlawful for a person to discriminate against another person, on the ground of the other person’s disability, by refusing to offer the other person:

(a) an annuity; or
(b) a life insurance policy; or
(c) a policy of insurance against accident or any other policy of insurance; or
(d) membership of a superannuation or provident fund; or
(e) membership of a superannuation or provident scheme;

if:

(f) the discrimination:

(i) is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; and
(ii) is reasonable having regard to the matter of the data and other relevant factors; or

(g) in a case where no such actuarial or statistical data is available and cannot reasonably be obtained—the discrimination is reasonable having regard to any other relevant factors.

(2) This Part does not render it unlawful for a person to discriminate against another person, on the ground of the other person’s disability, in respect of the terms or conditions on which:

(a) an annuity; or
(b) a life insurance policy; or
(c) a policy of insurance against accident or any other policy of insurance; or
(d) membership of a superannuation or provident fund; or
(e) membership of a superannuation or provident scheme;

is offered to, or may be obtained by, the other person, if:

(f) the discrimination:

(i) is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; and
(ii) is reasonable having regard to the matter of the data and other relevant factors; or

(g) in a case where no such actuarial or statistical data is available and cannot reasonably be obtained—the discrimination is reasonable having regard to any other relevant factors.

Public Health Act 1991 (NSW)

17 Protection of identity

(1) A medical practitioner must not state the name or address of a patient:

(a) in a certificate sent to the Director-General under section 14 in relation to a Category 5 medical condition, or
(b) except as may be prescribed, in a written or oral communication made by the medical practitioner for the purpose of arranging a test to find out whether the patient suffers from a Category 5 medical condition.

(2) A person who, in the course of providing a service, acquires information that another person:

(a) has been, or is required to be, or is to be, tested for a Category 5 medical condition, or
(b) is, or has been, infected with a Category 5 medical condition,

must take all reasonable steps to prevent disclosure of the information to another person.

(3) Information about a person that is of a kind referred to in subsection (2) may be disclosed:

(a) with the consent of the other person, or
(b) in connection with the administration of this Act or another Act, or
(c) by order of a court or a person authorised by law to examine witnesses, or
(d) to a person who is involved in the provision of care to, or treatment or counselling of, the other person if the information is required in connection with providing such care, treatment or counselling, or
(e) in such circumstances as may be prescribed.

(4) A medical practitioner or other person who fails to comply with the requirements of this section is guilty of an offence.

Maximum penalty: 50 penalty units.

Schedule 1 of the Public Health Act provides that a Category 5 medical condition is HIV or AIDS.
Public Health Regulation 1991 (NSW)

Definitions — Regulation 18...

“List ‘A’ disease” means any one or more of the following conditions:
- Acquired Immunodeficiency Syndrome (AIDS)
- Acute viral hepatitis (unspecified)
- Hepatitis B
- Hepatitis C
- Hepatitis D
- Human immunodeficiency virus infection (HIV infection)
- Meningococcal disease
- Rabies
- Tuberculosis;

“List ‘B’ disease” means any one or more of the following diseases:
- Anthrax
- Creutzfeldt-Jakob disease
- Diphtheria
- Plague
- Smallpox
- Yellow fever
- Any viral haemorrhagic fever (including Lassa, Marburg, Ebola and Congo-Crimean fevers);

Regulation 28 Removal of bodies from body bags

(1) An undertaker may remove from a body bag a body which the undertaker has no reason to believe is infected with a List “A” or List “B” disease for the purpose of:
   (a) embalming the body; or
   (b) preparing the body for viewing, transport, burial or cremation; or
   (c) transferring the body to a coffin.

(2) An undertaker may remove from a body bag a body which the undertaker has reason to believe is infected with a List “A” disease for the purpose of:
   (a) preparing the body for viewing, transport, burial or cremation; or
   (b) transferring the body to a coffin.

(3) After an undertaker has embalmed or prepared a body, the undertaker must place it in a coffin or in a new body bag approved by the Director-General.

Maximum penalty: 10 penalty units.

(4) A person must not remove from an outer body bag required under clause 26 (2) a body which the person has reason to believe is infected with a List “B” disease.

Maximum penalty—subclause (4): 10 penalty units.

Regulation 29 Body viewing

An undertaker may make available for viewing by mourners a body which the undertaker has no reason to believe is infected with a List “B” disease.

(2) However, an undertaker who makes an unembalmed body available for viewing:
   (a) must not remove the body from refrigeration for a period longer than is necessary for making it available for viewing; and
   (b) unless the body is to be buried or cremated immediately, must replace the body under refrigeration after the viewing; and
   (c) must not allow the body to remain unrefrigerated for a period exceeding 8 hours in any day.

Maximum penalty: 5 penalty units.

An undertaker is to refuse or terminate the viewing of a body if the undertaker has reason to believe that the viewing will be, or will become, prejudicial to public health or amenity.

An undertaker must not make available for viewing a body which the undertaker has reason to believe is infected with a List “B” disease.

Maximum penalty—subclauses (3) and (4): 10 penalty units.
Appendix G Reference List

Andriulli, A., Mangia, A., Niro, G. and Caturelli, E. 2001 To biopsy or not biopsy (letter to the Editor), Hepatology, Vol. 34, 438–439.


Australian Hepatitis Council 2001 The Australian media guide to hepatitis C, Canberra.


Australian National Council on AIDS and Intergovernmental Committee on AIDS and Related Diseases 2001 National Hepatitis C Testing Policy (Draft), Commonwealth Department of Health and Aged Care, Canberra. [Due for release by the end of 2001].


Burrows, B. and Bassett, B. 1996 Meeting the needs of people in Australia living with hepatitis C. National Hepatitis C Council’s Education Reference Group, Commonwealth Department of Health and Family Services, Canberra.

Cabassi, J. 2001 Barriers to access and effective use of anti-discrimination remedies for people living with HIV and HCV, ANCAHRD Occasional Paper No. 1, Canberra.

Carey, W.D., Saadeh, S. and Barnes, D. 2001 To biopsy or not biopsy (letter to the Editor), Hepatology, Vol. 34, 439.

Commonwealth Department of Health and Aged Care 2000 Hepatitis C: informing Australia’s national response, Canberra.


Department of Labour 2000 Managing health and safety risks in New Zealand mortuaries, Wellington, New Zealand.


Dore, G. 2000 Natural history of hepatitis C virus infection, Hepatitis C: informing Australia’s national response, Commonwealth Department of Health and Aged Care, Canberra.


Elmar Jaeckel, M.D., Markus Cornberg, M.D., Heiner Wedemeyer, M.D., Teresa Santantonio, M.D., Julika Mayer, M.D., Myrga Zankel, D.V.M., Giuseppe Pastore, M.D., Manfred Dietrich, M.D., Christian Trautwein, M.D., Michael P. Manns, M.D. and the German Acute Hepatitis C Therapy Group , Treatment of Acute Hepatitis C with Interferon Alfa-2b, The New England Journal of Medicine.<content.nejm.org> The article was published on line early because of its potential clinical implications. The article is to be published in the November 15, 2001 issue of the Journal.


Gifford, S., O’Brien, M., Banwell, C. and Bammer, G. 2001 Survey of women living with hepatitis C in Victoria and ACT, Deakin University, Australian Research Centre in Sex Health and Society, La Trobe University, National Centre for Epidemiology and Population Health, Australian National University.


A Better Health System for NSW, NSW Government.

Guidelines for counselling associated with HIV antibody testing, Circular 92/20.

HIV/AIDS and confidentiality: A guide to legal requirements, Circular 98/100.

Health care workers infected with HIV, hepatitis B or hepatitis C, Circular 99/88.

Infection Control Policy, Circular 99/87.


Medical practitioners & blood borne viruses — HIV, hepatitis B and hepatitis C, Sydney.

Report to NSW Minister for Health: Framework for Change, NSW Government.

Panacea or Placebo? Linked electronic health records and improvements in health outcomes, Report to the NSW Minister for Health, Sydney.


Teaching about hepatitis C: A national survey of secondary school teachers, Monograph series No. 18, Australian Research Centre in Sex, Health and Society, La Trobe University.


Enhanced Primary Care: Standards and Guidelines for the Enhanced Primary Care Medicare Benefits Schedule Items.


HIV and other blood-borne pathogens in the workplace.
## Appendix H
### Summary of recommendations by department or agency

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