

# *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.<sup>1</sup>

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.<sup>2</sup> 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.

**TABLE 2: Number of complaints lodged and telephone enquiries — Disability Discrimination Act\***

	1999–2000	2000–2001
<b>Telephone enquiries — organisms causing disease **</b>	<b>139</b>	<b>113</b>
<b>Complaints — organisms causing disease</b>	<b>7</b>	<b>16</b>
<b>Total DDA complaints</b>	<b>445</b>	<b>444</b>

\*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**

<sup>1</sup> 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.

<sup>2</sup> 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.<sup>3</sup>

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.<sup>4</sup>

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.<sup>5</sup>

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.<sup>6</sup>

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.<sup>7</sup> 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.

<sup>3</sup> 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.

<sup>4</sup> Ms Maureen Steele, Sydney hearing, 15 March 2001.

<sup>5</sup> Individual Submission, regional hearing, May 2001.

<sup>6</sup> Multicultural HIV/AIDS Service, Submission No. 64.

<sup>7</sup> 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.<sup>8</sup>

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, take 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.<sup>9</sup>

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.<sup>10</sup>

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 associated with pursuing complaints to a hearing where they are not resolved at conciliation.<sup>11</sup>

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.<sup>12</sup>

The NSW Combined Community Centre Group raise concerns about the capacity of individual complaints to adequately address systemic discrimination.<sup>15</sup> 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

## case study

'Paul' lodged a complaint alleging that he had been discriminated against on the basis of his HCV in the provision of insurance. He had been advised by the insurance company that it was the company's 'standard practice to deny cover to applicants that are hepatitis C positive.'<sup>13</sup> Paul had been advised that his case had good prospects of success. Paul submitted a number of offers to settle the matter, which were rejected by the insurance company. As the matter had not been resolved through conciliation, Paul would need to take the matter to court, which he could not afford to do. He had been assisted by a community legal centre, however, the centre did not have sufficient resources to represent Paul in a hearing. Paul was not eligible for legal aid. Paul applied to many of the private law firms' pro bono schemes, but all were unable to assist in the matter because they had a conflict of interest. The conflict of interest arose because all the private law firms Paul approached had undertaken work for the financial institution, of which the insurance company was a subsidiary.<sup>14</sup>

<sup>8</sup>HCC NSW, Submission No. 80.

<sup>9</sup>Lawyer, regional hearing, May 2001.

<sup>10</sup>Individual Submission No. 65.

<sup>11</sup>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*.

<sup>12</sup>Individual Submission No. 86.

<sup>13</sup>Discrimination in the provision of insurance is considered in detail in Chapter 2, section 2.6.

<sup>14</sup>Individual Submission No. 27.

<sup>15</sup>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 through 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.<sup>16</sup> 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.<sup>17</sup> 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.<sup>18</sup>

<sup>16</sup> HCC NSW, Submission No. 80.

<sup>17</sup> NUAA, Submission No. 68.

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.<sup>19</sup> 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.<sup>20</sup>

The ADB has made detailed submissions to the LRC's review and to the Attorney General in response to the LRC's report. 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 both original and appeal 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.<sup>21</sup> 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.<sup>22</sup> 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

<sup>18</sup> 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.

<sup>19</sup> *Review of the Anti-Discrimination Act 1977 (NSW)*, NSW LRC, Report 92, Sydney, 1999.

<sup>20</sup> *Review of the Anti-Discrimination Act 1977 (NSW)*, recommendation 125 at page 672.

<sup>21</sup> *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).

<sup>22</sup> *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.

- individual complaint-based systems are inadequate to address systemic discrimination.

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.**

**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.<sup>23</sup>

## 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.<sup>24</sup>

## 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

<sup>23</sup> The NSW Health Code is available on the NSW Health website, <[www.health.nsw.gov.au](http://www.health.nsw.gov.au)>.

<sup>24</sup> 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.<sup>25</sup>

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, inappropriate 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

<sup>25</sup> *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

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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.**

# *chapter* 5

## 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.<sup>1</sup> 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

<sup>1</sup> Heywood, M. and Altman, D. 2000 Confronting AIDS: Human rights, law, and social transformation, *Health and Human Rights — An International Journal*, Vol. 5, No. 1 at page 153.

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.<sup>3</sup> 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.<sup>4</sup>

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.



The intricate relationship between health and human rights embraces not only civil and political rights but — perhaps first and foremost — the right to health.<sup>2</sup>

<sup>2</sup> Mhloyi, M. 1995 Health and human rights: An international crusade, *Health and Human Rights — An International Journal*, Vol. 1, No. 2 at page 125.

<sup>3</sup> This historical context is considered in more detail in the Forward to this report.

<sup>4</sup> Tarantola, D. 2000 The shifting HIV/AIDS paradigm: 20 years and counting, *Health and Human Rights — An International Journal*, Vol. 5, No. 1 at page 2.