



Hepatitis C
Council of NSW

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The Secretary
House Standing Committee on Family and Human Services
House of Representatives
Parliament House
CANBERRA ACT 2600

Email to fhs.reps@aph.gov.au

29 March 2007

Dear Sir or Madam

INQUIRY INTO THE IMPACT OF ILLICIT DRUG USE ON FAMILIES

I enclose the submission from the Hepatitis C Council of NSW.

The Hepatitis C Council of NSW is the community based, non-government organisation and health promotion charity, funded by NSW Health to provide information, support, referral, education and advocacy services for and on behalf of people in NSW affected by hepatitis C.

We wish to make general comment on the areas of work examined by the Inquiry, and make specific comment on term of reference 2: the impact of harm minimisation on families.

In particular, we make comment on the role that harm minimisation plays in hepatitis C transmission prevention and on the far-reaching benefits Australia's Needle and Syringe Program has in this regard.

We are happy for our submission to be made publicly available.

Please contact me if we can provide further information or additional comment.

Yours sincerely

Stuart Loveday
Executive Officer

Hepatitis C Council of NSW
Submission to
House of Representatives Standing Committee on Family
and Human Services

INQUIRY INTO THE IMPACT OF ILLICIT DRUG USE ON FAMILIES

Contribution to the Inquiry

We wish to make general comment on the areas of work examined by the Inquiry, and make specific comment on term of reference 2: the impact of harm minimisation on families.

In particular, we make comment on the role that harm minimisation plays in hepatitis C transmission prevention and on the far-reaching benefits Australia's Needle and Syringe Program has in this regard.

Background

The Hepatitis C Council of NSW is the community based, non-government organisation and health promotion charity, funded by the NSW Health Department to provide information, support, referral, education and advocacy services for and on behalf of people in NSW affected by hepatitis C.

Established as a support group in 1991 by people with hepatitis C, the Council has always worked on behalf of all people affected by hepatitis C, whatever the route of transmission by which they acquired the hepatitis C virus.

The Council provides a range of services:

- information resources: booklets, factsheets, the quarterly magazine *The Hep C Review*, Australia's most widely read regular hepatitis publication and a highly regarded website www.hepatitisc.org.au
- education and workforce development: we provide education and capacity building services on hepatitis C for the NSW healthcare workforce and those in the allied workforce accessed by people with or at risk from hepatitis C
- information and support services: we operate the free and confidential *NSW Hep C Helpline* and *Prisons Hep C Helpline* and refer callers to a wide range of healthcare and welfare workers and support groups across NSW
- client support services: we host an online discussion forum and coordinate a peer-based treatment support service
- we advocate for improved access to management and treatment services and work in partnership with others in order to help improve treatment and services accessed by people with hepatitis C so as to improve the quality of their lives
- we advocate for and educate the community about preventing the transmission of hepatitis C

Hepatitis C – an overview

Hepatitis C is a blood-borne virus (HCV) that is transmitted when the blood of a person with hepatitis C gets into the bloodstream of another person.

Hepatitis C is not classified as a sexually transmitted infection and is rarely transmitted sexually.

Hepatitis C is one of Australia's fastest growing and most frequently reported notifiable communicable diseases. With over 95,000 *reported* cases in NSW alone and over 225,000 Australia-wide (at December 2005), hepatitis C represents a major threat to personal and public health, and comes at enormous cost to the health system. It has, for some years, been Australia's leading reason for liver transplants.

A blood-borne virus, hepatitis C causes inflammation of the liver and can in some cases cause very serious, life threatening liver damage.

Fortunately, for most people with chronic hepatitis C, the condition is manageable and non-life threatening, and the general community is not at risk of contracting hepatitis C unless people have blood-to-blood contact with other people with hepatitis C.

However, it causes major loss of quality of life in large numbers of people with chronic hepatitis C as a result of often debilitating symptomatic illness. That in turn has major personal and social impacts, through the creation of difficulties associated with living with a physiologically debilitating chronic health condition.

There is a major economic impact as well, through people with hepatitis C-related illness not being able to work full time or being unable to work at all. Lost productivity; healthcare costs for diagnosis, testing, management, treatment; social security costs; home and child care costs all mount up to cost individuals, families and Australian governments significant resources.

An often unrecognised cost is the personal and social and economic impact of the discrimination and stigma all too often endured by people with hepatitis C.

A far-reaching Enquiry (*C-change: Report of the enquiry into hepatitis C related discrimination*. Anti-Discrimination Board of NSW, November 2001) found 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 the Enquiry made 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.

A person with hepatitis C said in the foreword of the report:

“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 — so the fear is real.”

Discrimination, particularly in the healthcare setting where the Enquiry found it occurred most of all, has the effect of discouraging people from accessing healthcare services, and discourages them from looking after their own health needs generally.

Between 1% and 2% of the Australian population have hepatitis C. Particular communities have higher prevalence rates of hepatitis C prevalence. Indigenous Australians, and Australians from culturally and linguistically diverse backgrounds have higher rates of hepatitis C infection.

Out of the 264,000 people estimated to have contracted hepatitis C in Australia by Dec 2005,

- 82.3% or 218,000 people contracted it through blood-to-blood contact while sharing equipment used to inject drugs. (*Estimates and Projections of the Hepatitis C Virus Epidemic in Australia 2006*, Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis - Hepatitis C Sub-Committee Hepatitis C Virus Projections Working Group, October 2006)
- 29,000 people (10.9%) were estimated to be from countries of high prevalence who migrated to Australia with HCV antibodies – they would have contracted HCV largely through unsterile medical procedures including mass vaccination programs, conducted in their countries of origin.
- 18,000 people (6.8%) were estimated to have been exposed to HCV through receipt of contaminated blood (through transfusions or blood products receipt before screening of the blood supply began in February 1990) or through other routes of blood exposure such as unsterile tattooing or body piercing or mother-to-child transmission.

Hepatitis C incidence in 2005 was estimated to be 9,700 new infections. Out of these (almost) 10,000 new hepatitis C infections per year, 89% are exposed through injecting drug use, 7% are likely to be people born overseas and 4.4% are estimated to be infected through other blood-to-blood contact routes such as unsterile tattooing.

Of the estimated 264,000 people living with HCV antibodies in Australia at the end of 2005, it was estimated that:

- 67,000 (25%) had cleared their HCV infection
- 154,000 (58%) had chronic HCV infection with mild to moderate liver disease
- 38,000 (15%) had chronic HCV infection with moderate to severe liver disease
- 5,300 (2%) were living with HCV-related cirrhosis

During 2005 it was estimated that:

- 210 developed HCV-related liver failures
- 105 developed HCV-related liver cancer

Since the beginning of the hepatitis C epidemic in Australia in the early 1960s, it was estimated that 27,700 people with HCV antibodies had died, of whom 1,900 had died of HCV-related liver disease and 6,000 had died of drug overdose.

Hepatitis C-related morbidity was estimated to be substantial, corresponding to a total of 37,800 quality adjusted life years (QALYs) lost during 2005, with the majority of QALYs lost in people with stage 0/1 (mild to moderate liver disease) (77% lost) or stage 2/3 (moderate to severe liver disease) (19% lost) chronic HCV-infection.

In recent research carried out by Applied Economics for the Australian Government Dept of Health and Ageing, it was reported that in 2004/05 the estimated *prevalence cost* of hepatitis C was \$156m. This was based on an estimated 211,105 persons living with chronic hepatitis C (most of whom had mild liver disease). Prevalence cost relates to all costs associated with a disease during one identified year, and it includes research, prevention, care and treatment costs. It does not include consequential costs such as lost productivity, home care, social security and other related costs.

Almost 10,000 new HCV infections are estimated to occur in Australia each year. 75% of those new infections become chronic or ongoing. Many people who have chronic hepatitis C go on to develop serious liver disease. A small percentage, but many in number, will require liver transplants and many people will face early and difficult death.

It is clear that without a significant reduction in new hepatitis C cases, the personal, social, healthcare, and economic costs – and costs to Australian families – will continue to increase.

Harm minimisation

Harm minimisation is the primary principle underpinning Australia's National Drug Strategy.

Harm minimisation does not condone harmful drug use, whether of licit or illicit substances. It refers to policies and programs aimed at reducing drug-related harm. It focuses on both licit and illicit drugs.

The mission of the current National Drug Strategy 2004-2009 is to improve health, social and economic outcomes by preventing the uptake of harmful drug use and reducing the harmful effects of licit and illicit drugs in Australian society. It encompasses a wide range of approaches, including abstinence-based strategies.

Harm minimisation includes preventing anticipated harm and reducing actual harm. Harm minimisation is consistent with a comprehensive approach to drug-related harm, and it relies on maintaining a balance between demand reduction, supply reduction and harm reduction.

The National Illicit Drug Strategy was launched in November 1997 and forms a significant part of the national Drug Strategy. It provides a range of initiatives to combat illicit drug use through a focus on reducing the supply of drugs and on reducing demand.

Drug related harm can be defined as any adverse social, physical, psychological, legal or other consequence of drug use that is experienced by a person using drugs or by people living with or otherwise affected by the actions of a person using drugs. This includes families.

It was estimated (Collins and Lapsley 2002) that the economic costs associated with licit and illicit drug use in 1998-1999 amounted to \$34.5 billion, of which tobacco accounted for 60%, alcohol 22%, and illicit drugs 17%.

As defined in the National Drug Strategy, harm minimisation encompasses:

- **Supply reduction** strategies to disrupt the supply of illicit drugs and the control and regulation of licit substances. For example, prohibition and policing of the importation and trafficking of illicit drugs.
- **Demand reduction** strategies to prevent the uptake of harmful drug use, including abstinence-based treatments to reduce drug use: For example: schools-based education for young people not to initiate drug use, and rehabilitation treatment programs for people dependent on illicit drugs and opioid replacement pharmacotherapy treatment programs.
- Targeted **harm reduction** strategies to reduce drug related harm for individuals and communities: helping people who currently use illicit drugs to reduce the harm associated with their drug use. The most significant aspect of this component is Australia's Needle and Syringe Program (NSP)

As will become evident later in our submission, we consider it vital that a better balance is achieved between the three components of harm minimisation if strategies to combat illicit drugs and to reduce hepatitis C transmission are to be effective.

Australia's illicit drugs budget

Research (Moore 2005) has analysed the amount of money Australian governments spent in 2002-03 on strategies to minimise the harm associated with illicit drug use.

It is estimated that Australian governments spent \$3.2 billion in 2002-03 in relation to illicit drugs.

It analysed the costs in categories that align with the three arms of Australia's harm minimisation framework inherent in Australia's National Drug Strategy.

This included and took account of strategies implemented under the Tough on Drugs National Illicit Drug Strategy launched in November 1997. The Tough on Drugs strategy prioritises those activities that fit under the supply reduction and demand reduction components of the harm minimisation framework of the National Drug Strategy.

The research summarised expenditure on "proactive" strategies to combat illicit drug manufacture, importation, sale and use, and on "reactive" strategies dealing with the consequences of illicit drug use.

Proactive strategies include law enforcement and interdiction, prevention education, treatment and harm reduction approaches such as needle and syringe programs. This expenditure totaled \$1.3 billion in 2002-03.

Reactive expenditure is that dealing with the consequences of illicit drug use. It totaled almost \$1.9 billion in 2002-03 – the biggest component by far was crime related expenditure, on which Australian State and Territory governments spent \$1.65 billion.

Expenditure on the consequences of drug use was much larger than proactive expenditures.

Crime-related consequences alone form half of all expenditures. Health and other consequences are, by comparison, much smaller components.

Of the proactive expenditure, law enforcement, accounting for 42% of this type of expenditure, is the most significant category. When it is considered with interdiction, more than half of what Australian governments spend proactively pertains to enforcement-related activity.

Prevention (23%) and treatment (17%) each account for approximately one-fifth of these expenditures, while harm reduction (4%) and expenditure not elsewhere included (1%) are small components.

Illicit drug related expenditure 2002-03

<i>Proactive expenditure</i>	<i>Federal \$m</i>	<i>S&T \$m</i>	<i>Total \$m</i>
Prevention – mainly schools based drug prevention education programs	57.4	246.5	303.9
Treatment – drug rehabilitation treatment services, pharmacotherapy treatment programs; correctional treatment services; diversion strategies	65.0	164.2	229.2
Harm reduction – mainly needle and syringe programs	17.1	38.3	55.4
Law enforcement – mainly policing related to drug defined offences and drug related prison expenditure and on the Australian Crime Commission – costs of policing the use of drugs is included in the reactive category	65.6	493.3	558.9
Interdiction - police and customs	181.5	0.0	181.5
Other – research, policy administration, information services	9.9	8.5	18.4
Total proactive expenditure	396.5	950.8	1,347.3
<i>Reactive expenditure</i>	<i>Federal \$m</i>	<i>S&T \$m</i>	<i>Total \$m</i>
Crime related	0.0	1,650.0	1,650.0
Health related	104.4	45.2	149.6
Other – eg social security	61.9	0.0	61.9
Total reactive expenditure	166.3	1,695.2	1,861.5
Total expenditure	562.8	2,646.0	3,208.8

Source: Drug policy modelling project monograph 01: *What is Australia's "drug budget"? The policy mix of illicit drug-related Government spending in Australia*; Timothy J. Moore. Turning Point Alcohol and Drug Centre. December 2005

Hepatitis C – a major harm associated with illicit injecting drug use

From the perspective of the Hepatitis C Council of NSW and from the points of view of the very many community members and families with whom we have contact, one of the major harms associated with illicit drug use, specifically, injecting drug use, is the consequent infection with hepatitis C.

Studies of hepatitis C risk factors in Australia show that around 80% of prevalent hepatitis C infections are attributed to injecting drug use. Prevalence of hepatitis C among injecting drug users has ranged from 50% to 70% since the early 1970s. Hepatitis C incidence (the annual rate of new infections) in the 1980s and early 1990s among people who inject drugs has been estimated to be around 15% per year, with some evidence of a decline in HCV incidence in the late 1980s, but remaining stable during the mid-1990s to mid-2000s.

Hepatitis C is rife in Australian prisons. While between 1% and 2% of the Australian population have hepatitis C, in NSW prisons, 40% of male inmates

and 64% of female inmates have hepatitis C. Many people are imprisoned for drug related crime, and many prisoners have a history of injecting drug use. Rates of hepatitis C are higher in women's prisons because proportionately more women are incarcerated for drug related crime, given that women commit a narrower range of crime than men.

Better and more effective use of diversionary programs and community based sentencing for appropriate offenders would help fathers and mothers of children stay out of jail. This would be of increased benefit to families.

Hepatitis C – the means of prevention

Hepatitis C has been transmitting in Australia, primarily among people who inject illicit drugs, since the late 1960s – possibly earlier. Hepatitis C was formally identified only in 1989. Prior to that it had been known as non A – non B hepatitis, but there was no test available to detect its presence.

Australia was the second country in the world to introduce the then new hepatitis C antibody test screening into the blood bank in Feb 1990.

This simple and cheap blood test detects the presence of HCV antibodies – and shows evidence of past HCV exposure, not current HCV viral status. A more recent and more complex PCR (polymerase chain reaction) test that detects HCV RNA is the definitive marker of current hepatitis C infectivity.

The primary means of prevention of transmission of the hepatitis C virus are based on two cornerstone strategies: Australia's highly successful Needle and Syringe Program (NSP) and education, including peer education.

Australia's first NSP was introduced in 1987 in Sydney in response to the then emerging HIV epidemic. It soon expanded across all states and territories. As a result of this pragmatic public health-based intervention, HIV transmission among people who inject drugs has remained at an exceptionally low level.

Relatively few people who have ever injected drugs in Australia have contracted HIV. HIV prevalence among people attending Needle and Syringe Programs in Australia between 1999-2003 remained around 1%. In cities abroad, for example in New York USA where needle and syringe programs are not widely supported, rates of HIV prevalence among people who inject drugs have been higher than 50%.

This low prevalence of HIV among people in Australia who inject drugs has in turn meant that HIV/AIDS has not made inroads into the broader Australian community through ongoing sexual transmission of HIV. This is as a result of the exceptional effectiveness of NSP as a means of HIV prevention among people who inject drugs.

Australia's harm minimisation approach has resulted the containment of HIV/AIDS primarily among the communities of men who have sex with men, where education and condom use remain the key prevention approaches.

Needle and syringe programs have not been as successful in preventing HCV infections as they have in preventing HIV infections among people who inject drugs. This is due to two main reasons:

- The pre-existing large number of people with hepatitis C before NSP was introduced: many people contracted hepatitis C during the decades of the 1960s and 1970s and the 1980s – before needle and syringe programs were introduced, and with risk behaviours continuing, and new injectors sharing injecting equipment with people who already had hepatitis C
- The relatively higher infectivity of HCV compared with HIV: Hepatitis C is around 10 times more infectious than HIV, therefore ongoing risk behaviours where people share syringes and other injecting paraphernalia and where blood-to-blood contact occurs poses a significantly higher risk of HCV transmission.

However, if NSP had not been available, the numbers of people infected with hepatitis C would have been far, far higher than is currently the case.

And without a doubt, the HIV/AIDS epidemic would be at levels it is at in countries where Needle and Syringe Programs were not embraced as they were in Australia.

The public health success and, flowing on from that, the sheer economic success of Australia's Needle and Syringe Program is nothing short of remarkable.

A major study (*Return On Investment In Needle & Syringe Programs In Australia Report: Commonwealth Department Of Health And Ageing, 2002*) found that during the decade of the 1990s, Australia's Needle and Syringe Program prevented 25,000 HIV transmissions and prevented 21,000 hepatitis C transmissions.

The cost of the program to governments and community over those 10 years was \$150 million (2000 prices). As a result of those HIV and hepatitis C transmissions prevented, overall, total treatment costs *alone* over the life of cases of HIV and HCV avoided as a result of the Needle and Syringe Program are approximately \$7,808 million (before discounting). An estimated 4,590 people's lives were saved.

Put simply, for \$150 million spent on the Needle and Syringe program, up to \$7.8 billion was saved on treatment costs alone, lives were saved and enormous hardship was avoided.

Needle and Syringe Programs: drug use and public safety

Despite numerous research studies investigating the possibility of serious negative consequences, there is no convincing evidence that Needle and Syringe Programs increase illicit drug use. A 2004 review of potential unintended negative consequences associated with Needle and Syringe Programs found that the Programs:

- do not encourage more frequent injection of drugs
- do not increase syringe lending to other injecting drug users
- do not increase recruitment of new injecting drug users

- do not increase social network formation
- do not increase transition from non-injecting drug use to injecting drug use
- do not affect injecting drug users' motivation to reduce drug use

In Australia, the proportion of the population who reported having injected drugs in the last 12 months remained at 0.6% to 0.7% between 1995 and 2001 and had decreased to 0.4% in 2004. If Needle and Syringe Programs encouraged injecting drug use, it would be expected that, all other factors remaining equal, the proportion of the population reporting recently injecting drugs would have increased rather than decreased.

There is no evidence to suggest that Needle and Syringe Programs increase crime or violence.

Numerous studies have found no evidence that Needle and Syringe Programs increase the number of used needles and syringes discarded in public areas. There has been only one published case in the world of hepatitis C transmission after an injury from a discarded used needle in the community.

In Australia to date, there have been no cases published of a member of the public becoming infected with HIV, hepatitis C or hepatitis B after an injury from a discarded used needle in the community.

Why aren't retractable needles and syringes available to people who inject drugs?

Evidence based trials of retractable needles and syringes with injecting drug users were conducted in Australia in 2004. The trials were designed to assess the suitability and acceptability of retractable needles and syringes to injecting drug users.

The results indicated a number of technical limitations with the retractable needle and syringe technology piloted and an overall lack of retractable needles and syringes that are suitable to be used by injecting drug users.

Needle and syringe programs as health services for people who use drugs

NSPs are important points of contact for the highly marginalised populations of people who inject drugs because they provide harm reduction education and referral to drug treatment, medical, legal and social services. Many NSP clients have never been in contact with other health or social services.

The Australian Needle and Syringe Program Survey 2000-2004 found that the proportion of Needle and Syringe Program clients who participated in drug treatment had increased from 68% in 2000 to 76% in 2004.

Studies from the UK and the USA have found that Needle and Syringe Programs act as gateways to more traditional medical treatment for drug dependence for many clients, and that NSP attendance is associated with

substantially reduced injecting or cessation of injecting compared with people who inject and have never attended an NSP.

The beneficial impact of this particular aspect of harm minimisation on families is clear.

Needle and Syringe programs and education for drug users prevent HIV and hepatitis C infection. They prevent their drug using family members from getting chronic illness and disease associated with those infections. They serve as health services for marginalised people, enabling referral to and participation in mainstream health services and in drug treatment services.

Put simply: Needle and Syringe Programs save lives. They also save health systems, governments and society as a whole billions of dollars, for a minimal investment.

This investment, tiny in comparison with the cost of other aspects of minimising the impact of illicit drug related harm, is backed up by firm and irrefutable evidence of its success in achieving its aims.

Conclusion

We very much hope the House of Representatives Standing Committee on Family and Human Services will inquire next into the impact of licit drug use on families. As we noted earlier and as has been reported extensively in the academic literature and general media, the cost of tobacco and alcohol to families, individuals, health services and society as a whole is far, far greater than that resulting from illicit drug use.

While we acknowledge there is substantial harm associated with illicit drug use, we believe there should continue to be a balanced approach to formulation and implementation of government policy and practice in relation to it. Above all, responses should be evidence based, and they should show compassion, effectiveness, safety and cost-effectiveness.

We know from ongoing incident hepatitis C infections that there is a vital need to expand dramatically the means of preventing hepatitis C transmission and to maintaining low HIV infection rates among people who inject drugs.

Given the extreme imbalance of investment between the three components of the harm minimisation approach of supply reduction, demand reduction and harm reduction, we call on this Inquiry to recommend that governments increase funding for health and social interventions to the current level of illicit drug law enforcement and to fund interventions on the basis of evidence of effectiveness and safety and improving the return on substantial government investment.

We call on this Inquiry to recommend that governments commit significantly more resources to the harm reduction arm of the National Drug Strategy, in particular, to increase funding to ensure greatly enhanced coverage of and access to the Needle and Syringe Program in Australia and to support the research required to identify optimal ways of achieving this.

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