

***Submission to the House of Representatives
Standing Committee on Family and Human Services
Inquiry into the Impact of Illicit Drug Use on Families***

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1. Introduction

The Australasian Society of HIV Medicine (ASHM) is a professional association for those who work in the area of bloodborne viruses (BBV - HIV and viral hepatitis) spanning a wide variety of fields and disciplines. The organization's vision is to lead its members to generate knowledge and action in clinical management and research, education, policy and advocacy across Australasia and internationally. Through this, ASHM will prevent HIV, viral hepatitis and sexually transmissible infections (STIs) and preserve and protect the health and choices of those who are infected. The main ways ASHM will do this are through:

- providing information, education and training to its members and to the relevant health sectors
- providing career assistance and recruiting new people to the field
- supporting networking and collaboration between different professional groups
- promoting a policy framework that assists members' work and contributes to a strong, relevant and effective public health response

The society's purpose, set out above, provides a framework for its response to the Inquiry into the Impact of Illicit Drug Use on Families by the House of Representatives Standing Committee on Family and Human Services.

The Committee has set out its terms of reference for submissions. It will inquire into and report on how the Australian Government can better address the impact of the importation, production, sale, use and prevention of illicit drugs on families. The Committee is particularly interested in:

- the financial, social and personal cost to families who have a member(s) using illicit drugs, including the impact of drug induced psychoses or other mental disorders;
- the impact of harm minimisation programs on families; and
- ways to strengthen families who are coping with a member(s) using illicit drugs.

This submission from ASHM will provide a background and address:

- illicit drugs and the impact of harm reduction programs on the transmission of bloodborne viruses (BBV), and costs to individuals and families;
- illicit drugs and their impact on the clinical management of people with BBV and costs to individuals and families.

2. Background

2.1 Drug use in Australia

Recent studies report that approximately 38% of the Australian population aged 14 years and over had used any illicit drug at least once in their life and 117% had used any illicit drug at least once in the previous 12 months. Marijuana was the most commonly used illicit drug (13% in last year), followed by amphetamines (3% in last year). Fewer than 1% had used heroin in the preceding 12 months. In contrast, approximately 20% of all Australians over 14 years were daily smokers and only half the population had never smoked. Approximately 40% of women and 60% of Australian men 14 years and over reported drinking at least weekly (AIHW 2003).

Drug use, licit or illicit is highly individualized in Australian society. Patterns and trends are reported at a population level and are useful in developing population based responses (for example, male, 20-29 years old, poly drug user, licit and illicit, lower socio-economic status). However, this does not capture the variety of drug using behaviours nor the range of consequences on the individual or family. Families, friends and service providers are living and dealing with individuals who may use a drug/s covertly or overtly; whose use is infrequent and irregular or habituated and escalating; whose personal, family and social life is damagingly influenced or alternatively not adversely affected by their drug use (Victorian Government Department of Human Services 2006).

Gay men across the country use illicit drugs at levels well above the general population (marijuana, amyl nitrite most commonly). Additionally, they also inject drugs at higher rates than the general population, although there is evidence of a slight decline in injecting drugs. Both legal and illicit drug use are associated with unprotected anal intercourse, although a causal relationship has not been defined. Drug use is also associated with various other indicators of 'adventurousness' or 'partying hard', but a causal relationship cannot be drawn from this. HIV infections are also associated with drug use. For HIV-negative men who engage in unprotected anal intercourse, drug use may not be the key factor in whether they choose to use a condom or not on a particular occasion. For a significant minority of men their drug use is of concern and may also be a factor in their risk behaviour. (*G. Prestage pers comm*)

In HIV positive gay men, illicit drug use was no greater in encounters in which a condom was not used than those in which a condom was used for insertive anal intercourse. (Prestage 2007)

There are groups in society who are defined as being at greater risk of drug and BBV related harms, they include: injecting drug users (IDU), men who have sex with men, young people, Indigenous people and prisoners.

2.2 Drug related mortality and morbidity in Australia

It has been estimated that in Australia in 1998, there were approximately 1,000 deaths (mortality) attributed to illicit drugs. In contrast, there were 19,000 deaths attributed to tobacco and 330 deaths due to alcohol. A comparison of estimated years of life expectancy lost to drugs, 55% of these lost years were attributed to tobacco, 34% to alcohol and 11% to illicit drugs. (AIHW 2003)

Impact of drugs on life and health is far-reaching. Hospital bed-days are regarded as one of the best readily-available proxies for disease (morbidity). Figures from 1997–98, attribute approximately 200,000 hospital episodes were to any drug use. Approximately 143,000 were due to tobacco use, 43,000 to alcohol use and 14,000 to illicit drug use. (AIHW 2003)

For illicit drug use related hospitalisations in 1997–98, drug dependence (which would include treatment) accounted for 6,336 hospital episodes (44%) and poisoning accounted for 2,439 hospital episodes (17%). (AIHW 2003) Disability Adjusted Life Years (DALYs) are a measure of the total health burden of a disease or injury. In Australia in 1996, tobacco accounted for 9.7% of total DALYs with alcohol responsible for 4.9% and illicit drugs for 1.8%. (Mathers 2000) The burden of mental disorders in Australia is dominated by affective (depression and bipolar disorder), substance use and anxiety disorders. Substance use disorders are the leading cause of mental disorders for males, accounting for 33% of their mental health DALYs. (Mathers 2000)

In Australia, illicit drug users frequently use licit drugs. The relative burdens of this poly-drug use on individual morbidity and mortality, the families and friends of these individuals or the community are not always clear.

2.3 Bloodborne viruses in Australia

2.3.1 HIV infection

In Australia, there have been more than 22,000 cases of HIV infection reported, approximately 10,000 cases of AIDS and nearly 7,000 deaths from HIV up until the end of 2005. It is estimated that in 2005 there were 15,000 people living with HIV and approximately 7% are women. There has been a gradual increase in the number of HIV cases diagnosed each year, from 635 in 2001 to nearly 1000 in 2005, including a greater proportion that had recently acquired their infection. (National Centre in HIV Epidemiology and Clinical Research 2006)

Sexual contact between men remains the major mode of HIV transmission in Australia. For newly diagnosed HIV infection (infection may have actually been acquired some years before diagnosis) a history of male homosexual contact was reported between 2001 - 2005 in 64% of cases, 4% of cases occurred in homosexual men who injected drugs. The reported mode of transmission for cases of newly acquired HIV infection (infection was acquired within the previous 12 months, a smaller number) was:

- male homosexual contact in 86%,
- drug use in homosexual men in 4%,
- injecting drug use among women and heterosexual men in 2%,
- heterosexual contact only in 9% and,
- in 3% of cases, exposure to HIV remained undetermined.

Between 1996 – 2005, approximately 8% of HIV diagnoses in Australia were in people with a history of injecting drug use; more than half were men who also reported a history of homosexual contact. HIV prevalence among people attending Needle and Syringe Programs has remained low (around 1% in 2001 – 2005) but in a small study of a subgroup of men who identified as homosexual, it was 20.8% in 2005. A single case (0.03%) of HIV was diagnosed through testing over 3,500 men and women, with a history of injecting drug use, attending metropolitan sexual health centres. (National Centre in HIV Epidemiology and Clinical Research 2006)

Approximately 70% of all people living with HIV infection were receiving antiretroviral treatment for HIV infection in 2005. Combination drug therapy against HIV has been very effective in delaying the progression of the infection to AIDS in the last 10 years. In the

absence of a cure, it is anticipated that treatment will need to be uninterrupted and lifelong. The long term sequelae of this treatment have not been determined. (National Centre in HIV Epidemiology and Clinical Research 2006). Drug treatment for HIV comprises multiple drugs with frequently complicated dosing regimens and side effects. Side effects may need to be managed with other drugs, adding to the therapeutic load and potential for dosing mistakes. For best effect, compliance should be high, drug resistance may develop otherwise, necessitating a therapeutic change (general to a regimen that is less 'user-friendly').

2.3.2 Hepatitis C infection

It has been estimated that in 2005, more than 250,000 Australians have been infected with hepatitis C virus, 197,000 of them have chronic hepatitis C infection, including 43,400 with moderate to severe liver disease. The majority (82%) was estimated to have been exposed through injecting drug use, 11% were migrants from countries of high HCV prevalence, and 6.8% were recipients of contaminated blood or blood products or exposed via other transmission routes. (National Centre in HIV Epidemiology and Clinical Research 2006a)

The rate of diagnosis of hepatitis C infection declined from an estimated 105.6 per 100,000 (20,031) to 63.4 per 100,000 population (12,594) from 2001 to 2005. Rates declined by nearly 50% in the 20-29 year old age group and by 40% in the 30-39 year old age group between 2001-2005. The rate of diagnosis of newly acquired infection in 15-19 year olds, decreased by 68% in 2001 to 2005. This fall in the rate of diagnosis may be due to a reduction in risk behaviour related to drug injecting among young people, but the possible contribution of changes in the rates of testing cannot be excluded.

Adults aged less than 30 years continue to have the highest rate of transmission of hepatitis C virus. This is primarily in people with a history of injecting drug use. Surveys of people who reported having injected for three years or less at Needle and Syringe Programs, show an increase in hepatitis C prevalence from 13% in 1996 to 26% in 2000. It remains steady at about 25% indicating continuing high levels of hepatitis C transmission in this population. The decline in the number of people reporting having injected drugs for three years or less (from 282 in 2001 to 88 in 2005) and the decline in the number of people aged less than 20 years (from 168 in 2001 to 41 in 2005), suggests a decline in the prevalence of injecting drug use among young people. (National Centre in HIV Epidemiology and Clinical Research 2006a)

Liver transplant for advanced chronic hepatitis infection is a de facto marker of morbidity. In 2005, from 133 people, approximately 38% of individuals who received a liver transplant had hepatitis C infection and 11% had hepatitis B. Liver cancer secondary to hepatitis B and C is the fastest growing cancer in Australia. (Robotin 2007)

Treatment for 6-12 months for hepatitis C infection is available in Australia. This treatment is curative in 50-70% and therefore has the advantage of a) improving health outcomes and quality of life and b) preventing viral transmission. Service availability, however, appears to be the rate limiting step for treatment uptake. It is estimated that there are only 3,500 people on treatment in Australia in 2007, out of a much bigger pool of eligible candidates.

2.3.3 Hepatitis B infection

Hepatitis B infection may be acquired through sexual, parenteral (such as sharing injecting equipment) and mother-to-child-exposure. It is considerably more infectious than HIV (100 times) and hepatitis (10 times) C and is vaccine preventable (now the vaccine is universally administered at birth). It is estimated that the rate of diagnosis of newly acquired hepatitis B infection in the Australian population has halved, from 2.3 per 100,000 in 2001 to 1.2 per 100,000 in 2005. Newly acquired hepatitis B infection attributed to injecting drug use remained stable at around 45% in 2002 – 2005. The percentage of diagnoses attributed to sexual contact increased from 25.3% in 2001 to 33.7% in 2005 and the percentage of diagnoses with an undetermined source of exposure declined from 22.7% in 2001 to 15.3% in 2005. (National Centre in HIV Epidemiology and Clinical Research 2006) A high proportion of these diagnoses are made in people in whom infection is preventable by administering the vaccine.

In Australia, the prevalence of chronic hepatitis B is estimated at between 0.5 – 0.8 per cent (O'Sullivan 2000), and about 1,200 people die of the sequelae each year (Gust 1992).

Drug therapy is available for hepatitis B infection. Treatment consists of antiviral drug(s) with their own side effects. Current therapies do not eradicate hepatitis B virus, so long-term treatment is usually required. Development of drug resistance is a major concern with long-term treatment. Even with successful therapy, patients remain at risk for reactivation of viral replication and require lifelong monitoring.

An important feature of Australians infected with HIV, hepatitis B or C, the viruses' impact on family and friends, their medical management, the role of illicit drug use and its treatment, is that even if injecting drug use was the cause of infection, the pattern of injecting drug use is that for most people it is not a life long activity. The majority of Australians living with these chronic, bloodborne infections do not inject drugs.

2.4 Harm minimisation

A harm-minimisation approach, as it is applied to drug use, considers the actual harms associated with the use of a particular drug (as well as, but not exclusively of the drug itself), and how these harms can be minimised or reduced. It recognises that drugs are, and will continue to be, a part of our society and that prohibition has historically been a counterproductive policy. Using a variety of strategies, harm minimisation works to reduce the harmful consequences of drug use, by reducing:

- demand for drugs (primary prevention)
 - supply of drugs
 - drug harms (secondary and tertiary prevention that provides assistance to people who use drugs to do so in the safest possible way, including referral for treatment).
- (Australian Drug Foundation)

Harm reduction, as exemplified by needle and syringe programs, has been demonstrated to be an effective, and cost effective strategy to prevent transmission of HIV and HCV in Australia (Health Outcomes International 2002) and consequent illness, with its direct and indirect costs for individuals and family and death.

In contrast, in the United States, where needle and syringe programs are uncommon, more than 20% of cases of HIV infections reported occur in IDUs. (MMWR 2006) It is estimated that a significant proportion of their sex partners or their children may become infected with HIV as well. Nearly 15% of all HIV cases occur in women with a high risk heterosexual exposure (usually with an IDU (MMWR 2004).

Needle and syringe programs are a significant strategy against the prevention of BBV, especially HIV in Australia. They have the additional, well recognised effect of providing IDUs with a health education and referral service. IDUs are known for not demonstrating 'health-seeking behaviour', even that is to their benefit, usually because of their experiences of being stigmatising within services. Individuals who do not access services that can improve their health status also affect the health and well being of their families. Needle and syringe programs can support and guide their clients who need assistance and support.

2.5 Costs

Estimates of the total costs of drug abuse comprise avoidable and unavoidable costs. Unavoidable costs comprise the costs which are currently borne relating to past drug abuse,

together with the costs incurred by the proportion of the population whose level of drug consumption will continue to involve costs.

Avoidable costs are those which are amenable to public policy initiatives and behaviour changes. These include personal, social and financial costs.

It is beyond the scope of this paper to provide an analysis of the costs of illicit drug use and bloodborne viruses as they relate to infected and affected individuals, rather to provide a perspective of what can be reasonably expected from public health interventions, and what cannot. This paper can emphasize the complexity of any cost analysis and remind the inquiry of the impact of indirect costs (that are difficult and less frequently measured) on the health and quality of life of drug users and their families and the need for further research to provide economic assessments that can inform and support users, former users and their families.

2.6 Families

The definition of family is at times controversial. Traditionally accepted as consisting of a domestic group of people (or a number of domestic groups), who are affiliated by birth or marriage, or by comparable relationships. This definition is rather exclusive of individuals whose social and community and domestic relationships are non-traditional.

In Australia, many members of the gay community, for example, are marginalised and may be estranged from their blood relatives or biological families. This has resulted in a re-definition of family for them, based on domestic and social arrangements. People who inject drugs and those with HIV or hepatitis also experience this estrangement.

In the absence of a 'functional' biological family, others step into the breach to fulfil the role of family members and thereby encounter the same difficulties and challenges of caring about and for someone who does not or cannot manage and maintain their health and lifestyle in a generally accepted way. This definition is used in this paper.

3. Transmission of BBV

The mode of transmission of BBV in Australia has already been outlined. It is important for families with members who inject drugs to understand factors that promote transmission and how these might be reduced or avoided all together. Below are some very simple examples, however family members have a duty to be informed of potential risks for their at-risk family member and themselves.

Transmission, for example, can be avoided by:

- a) not sharing injecting equipment. For example by not using drugs or using less, by not injecting drugs (eg smoking heroin instead) or injecting less, by using any injecting equipment before others – before others, by using only one's own equipment.;
- b) always having protected sex
- c) vaccination for hepatitis B
- d) always using universal precautions for body fluid spills,
- e) not sharing toothbrushes or razors.

Education for health service providers and peers (through community based organizations) to effectively deliver such information about secondary prevention techniques is fundamental to the effective implementation of a strategy.

4. Treatment for BBV infections

4.1 The management of HIV infection

There has been a dramatic decrease reported in the number of AIDS cases in Australia. Highly active antiretroviral treatment (HAART) for HIV has delayed the progress of disease and allowed HIV infected individuals to enjoy an improved health status with social, economic and personal benefits that was not previously available. Between 2001 and 2005, it has been estimated, using data from the Highly Specialised Drugs Program that the total number of people prescribed antiretroviral treatment for HIV infection increased from 7,619 to 10,841 (approximately 42% increase). HIV drug regimens have improved over the last few years, however there is still little flexibility associated with them and HIV+ individuals are required to adhere to them to ensure a maximal benefit.

4.2 The management of Hepatitis C infection

Antiviral treatment for hepatitis C represented a major advance in the management of this otherwise chronic condition. Treatment over 6 to 12 months offers a cure for approximately 50-70% of patients. Unfortunately, only a small proportion of Australians with hepatitis C infection that is eligible for treatment, is receiving it (an estimated 3,500 people were receiving treatment for hepatitis C infection in 2007). Since the removal of liver biopsy as a prerequisite to treatment in March 2006, the number has increased by approximately 1,000. (Batey 2007)

The decision to commence treatment is not taken lightly, most people take many months to actually start, after making the decision. Treatment with hepatitis C requires considerable commitment from those prescribed the drugs, their families, friends and colleagues. The side effects of the drugs can be very disruptive, ranging from general lethargy and malaise to major cardiovascular, metabolic and mental health disturbances. People on treatment find that their daily activities are interrupted and need to be curtailed (for instance employment, social activities) and that their relationships suffer because of the effect of feeling unwell all the time. Currently, only a single course of treatment is funded in Australia, therefore people with hepatitis C effectively have one opportunity for cure. It is most important that this chance of success is maximised for them and their families by ensuring support services are available.

For those with liver cirrhosis or hepatocellular carcinoma, treatment options are few. Liver transplantation for advanced chronic hepatitis infection may be offered. In 2005, from 133 people, approximately 38% of individuals who received a liver transplant had hepatitis C infection and 11% had hepatitis B.

4.3 Treatment of BBV and drug use – issues for consideration

Clinically the use of licit and illicit drugs for HIV and HCV infected individuals may adversely affect their health because of:

- a) difficulties accessing treatment services and initiating therapy, especially those that can provide drug and alcohol services (D&A) and contending with the 'double stigma' of D&A and BBV related health problems
- b) difficulties with drug and 'medication' interactions (HIV and HCV treatment with drug and alcohol, including drug treatment such as methadone, HIV and HCV treatment with psychotropics and drugs and alcohol with psychotropics)
- c) difficulties with treatment adherence and consequent clinical management because of drug side effects or 'chaotic lifestyles' etc
- d) greater morbidity and mortality in HIV infected patients with drug use disorders
- e) drug use disorders impact on the effectiveness of self care strategies
- f) comorbid psychiatric conditions are common, for example depression, anxiety disorders, bipolar disorders, personality disorders and some psychiatric conditions more associated with particular drugs eg amphetamines and depression.

Family members, of course, may be drawn into the difficulties of assisting in the management of one or a number of chronic health conditions. They may take on the responsibilities of part or fulltime carers that may result in financial, personal and social hardship. This can be

complicated by the presence of psychiatric conditions. Social factors (eg absence of poverty, stable housing) have been found to be important in improving and maintaining treatment adherence and then clinical outcomes.

At the time of diagnosis and treatment, individuals may 'come out' to their families about potentially stigmatising behaviours regarding sexuality and drug taking. These can have emotional and personal costs for all.

The direct and indirect costs of illness to individuals and their families vary with individual circumstances. It is important that programs that provide comprehensive treatment and support for BBV and D&A issues and other conditions are available. People who use drugs and their families need to be helped to understand the difficulties of drug treatment and relapse. Families require support to help their family member as appropriate and to be helped if the clinical course of the various conditions is not as straightforward as hoped.

5. Conclusions

Individuals who use or have used illicit and licit drugs may and do function effectively in our society, others require support from the community, family, friends and an array of professionals. For a proportion, they are at risk of infection with BBV and resultant chronic illnesses. Attached to this are the sequelae of managing their health from the point of view of the infection, the drug use and (often) mental health conditions. In turn, they must contend with financial disadvantage and the social and health difficulties that arise and compound this. Families of people who use illicit drugs deal with the same range of problems and are frequently ill-equipped. As well as witnessing a family member facing stigma and discrimination, they may in fact be guilty of this too, leading to family breakdown arising from fear and ignorance.

ASHM believes that efforts to minimise the effects of licit and illicit drugs on the health of Australians, especially in the area of BBV must continue and be strengthened. Responses include improved community education drugs and BBV, targeted education to those at greater risk, supportive education for those witnessing the effects. Harm reduction programs (such as needle and syringe programs) and treatment referral are essential. There is still a great need for the provision of comprehensive services for BBV, D&A and mental health conditions through primary health care providers – and they need the education and training to undertake this. There are serious service gaps in rural and remote Australia that must be filled by practitioners with skills in these areas.

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