Barriers and Incentives to Treatment for Illicit Drug Users with Mental Health Comorbidities and Complex Vulnerabilities

**Monograph Series
No. 61**

*National
Drug Strategy*

Barriers and Incentives to Treatment for Illicit Drug Users with Mental Health Comorbidities and Complex Vulnerabilities

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Contents

List of Tables

Barriers and Incentives to Treatment for Illicit Drug Users with
Mental Health Comorbidities and Complex Vulnerabilities

Acknowledgments

Conducting a study of this scope and complexity would not have been possible without the help and support of many different people. The project team thanks all who assisted them, whether they provided strategic advice on the conduct of the study, assisted in recruitment or data collection or commented on the study's policy implications. Special thanks go to:

- All the service users and providers who gave us their time to participate in interviews.

- The treatment services in Bathurst, Brisbane, Sydney and Perth who allowed us to advertise the project to their clients and staff.

- Skye Jewell at the Australian Injecting and Illicit Drug Users League (AIVL), for her energy, enthusiasm and skills in developing and managing the peer recruitment process.

- The peer recruiters who granted us access to their networks and handled the recruitment process so efficiently.

- The staff and volunteers at the New South Wales Users and AIDS Association (NUAA), the Queensland Injectors Health Network (QuIHN), and the Western Australian Substance Users Association (WASUA), who provided safe spaces for interviewing and advice on local recruitment.

- Jane Fischer and Shelley Cogger at Queensland Alcohol and Drug Research and Education Centre (QADREC) for their invaluable assistance in executing the Brisbane phase of the study.

- Anne Bartu at the Drug and Alcohol Office, Western Australia, for her advice on setting up the study in Perth.

- Rodney McDonald, Louise Redsull, Melissa Saxton and Laura Small at the National Centre in HIV Social Research (NCHSR) for their assistance in transcription, data cleaning and service provider recruitment.

- Tania Browne at the Australian Government Department of Health and Ageing for her consistent commitment to the project.

Acronyms

AIVL	Australian Injecting and Illicit Drug Users League
AOD	Alcohol and other drugs
GP	General practitioner
NCHSR	National Centre in HIV Social Research
NUAA	New South Wales Users and AIDS Association
QADREC	Queensland Alcohol and Drug Research and Education Centre
QuIHN	Queensland Injectors Health Network
UNSW	University of New South Wales
WASUA	Western Australian Substance Users Association

Chapter 1:
Executive summary

This study employed a qualitative research methodology to investigate barriers and incentives to treatment for people who use illicit drugs and who are living with mental health problems and other complex vulnerabilities, from the perspective of both service users and providers. The focus of the study was on service users with high prevalence mental health problems, particularly anxiety and depression.

This study was funded by the Australian Department of Health and Ageing under the National Comorbidity Initiative to:

- identify the barriers and incentives to treatment for people who use illicit drugs and those living with mental health comorbidities and complex vulnerabilities

- identify treatment options that are mutually advantageous to people who use illicit drugs and treatment service providers

- develop a set of practical recommendations regarding possible policy and program directions arising from the research findings.

The study was conducted between August 2004 and August 2006. The project partners were LMS Consulting, the National Centre in HIV Social Research at the University of New South Wales and the Australian Injecting and Illicit Drug Users League.

1.1   Method

Study elements included:

- a review of the Australian literature and selected international literature and the preparation of a discussion document

- advice from an Expert Reference Network

- semi-structured in-depth interviews with a total of 77 service users and 18 service providers in four sites (Sydney, Bathurst, Brisbane and Perth)

- a one-day key informant workshop to discuss the preliminary findings of the qualitative study and to identify options for improved treatment service delivery.

1.2   Results from service user interviews

The vast majority of service user participants (95%) had been diagnosed with depression and reported a wide range of symptoms. Twenty-nine per cent had been diagnosed with anxiety. The main themes from the service user interviews were:

1.2.1   Service users' understanding of drug and mental health problems

While service users were able to provide narratives about their illicit drug use and treatment experiences, they were much less able to describe their experience of mental health problems. Issues that may have prevented their acknowledgment and understanding of their mental health difficulties included: reluctance to face the additional stigma of being seen as 'mentally ill'; drug-related problems taking precedence; and poor understanding of mental health diagnoses, especially clinical terminology such as 'comorbidity' and 'dual diagnosis'.

Participants described a wide range of deleterious symptoms of depression and anxiety, some of which (e.g. mood swings, feeling unable to deal with other people, lack of motivation) directly affected their ability to attend or participate in drug treatment.

In accounting for their mental health problems, some participants believed these originated in childhood or family experiences, while others talked about stressful life events or contextual triggers. Some participants described how they had used illicit drugs to manage or mask the symptoms of anxiety or depression (self-medication), while others believed that their illicit drug use was implicated in the emergence or intensification of their problems with anxiety or depression.

1.2.2   Drug treatment services

Many study participants had attempted to get support for their anxiety or depression through a drug treatment service. However, the majority reported that access to mental health support or treatment was poorly managed by drug treatment services. Challenges identified by service users included:

- lack of interest in, knowledge of, or expertise in mental health issues by drug treatment services
- difficulties in accessing mental health services through drug treatment services (in-house or by referral to external services)
- a focus on drug-related issues to the exclusion of mental health problems
- a tendency for drug treatment services to trivialise service users' mental health concerns.

Methadone clinics in particular were singled out as being variously too busy, under too much pressure, uninterested in, unwilling, or unable to deal with service users' mental health problems. Consequently, most of the service user participants stated that they tried to interact as little as possible with methadone clinics, unless an obviously engaged and sympathetic staff member could be identified.

Despite their negative experiences with methadone clinics, many service users reported that substitution treatment had enabled them to achieve a more stable family and working life, and had therefore assisted them in reducing the symptoms of anxiety and depression.

1.2.3   Mental health treatment services

For those participants who had attempted to access mental health services directly, the common chronic nature of anxiety or depression tended to be the most obvious barrier to accessing treatment. Unless the service user was judged to be a threat to themselves or others, it was difficult to gain access to public mental health services, and few could afford private treatments.

1.2.4   General Practitioners

Some participants sought help for their mental health problems directly through a GP, either because of an existing trusted relationship or because they could not get support from mental health or drug treatment services. Difficulties encountered included finding a suitable or sympathetic GP, lack of GP training in drug and mental health problems, GP

over-reliance on prescribing medications, and waiting times. Where trust and therapeutic relationships had been established, GPs were described as 'fabulous' and 'indispensable'. However, many participants did not have a regular GP and were reticent to disclose information relating to drug use in a general practice setting.

1.2.5   Integrated services
Few participants in the study received help for both their drug and mental health problems in the same place, from the same team or in an integrated way. Those who were able to access larger, more integrated treatment services reported favourably on the support they received for their mental health problems, often through in-house counsellors, a well organised case management system or through referrals to other organisations.

1.2.6   Pharmacological treatments
The service users recruited for this study could be regarded as a 'highly medicated' group. Nearly all (91%) had received substitution pharmacotherapy during their drug treatment history, and treatment by medication was overwhelmingly the most common way that participants' mental health problems were dealt with by drug treatment, mental health and GP services.

1.2.7   Antidepressant medication
The majority of the participants who had been diagnosed with depression had been prescribed antidepressants as a frontline treatment. The main positive effect of taking antidepressants as reported by participants was a reduction in the severity of the symptoms, giving participants a greater ability to manage their lives. Adverse side effects, apparent ineffectiveness of the medication, and not being able to afford prescriptions were commonly reported and cited as reasons for stopping medication.

1.2.8   Anti-anxiety medication
The fact that most service user participants had a history of drug dependence, together with the risk of developing dependence on tranquillisers, often meant that it was difficult for participants diagnosed with anxiety disorders to get appropriate medication. Many reported problems in taking tranquillisers. The ease with which dependence on tranquillisers could be developed was described as 'scary' and 'insidious' by service users, and lax or inconsistent prescribing practices were perceived to be implicated in these problems.

1.2.9   Counselling and other mental health treatments
Service users described experiences with a broad range of mental health professionals, including counsellors, therapists, mental health nurses, psychologists and psychiatrists. Experiences were varied. Positive experiences were linked to establishing trust with the therapist, perceiving the counsellor as genuine, non-judgmental and having relevant experience, and offering continuity of care. Therapies that included the development of symptom management and problem-solving techniques were valued. Negative experiences were linked to counsellors' judgmental attitudes, difficulties of establishing regular access, and a perceived lack of counsellor experience. Self-consciousness, anxiety and cynicism over efficacy were cited as reasons for service user reluctance to participate in group counselling sessions.

1.2.10 Self-management of comorbidity

Given the difficulties in accessing support for their mental health problems, service users developed a range of counsellor-driven and lay/practical strategies to manage their mental health problems. Many also self-medicated with alcohol or other drugs as a way of coping with their anxiety or depression, although it was acknowledged that this approach was problematic.

1.2.11 Complex vulnerabilities

In talking about their experience with both drug and mental health problems, service users described other aspects of their lives that adversely affected their ability to engage and remain in treatment. These included, but were not restricted to other health conditions including hepatitis C, poor housing conditions, restricted income and debt, having a criminal record, family issues and relationship problems. These 'life issues' formed a complex web of problems that service users learnt to negotiate with little support from treatment services.

1.2.12 Drug user organisations and peer support

Those service users who had experienced peer support and peer-led education (delivered by drug user organisations) were extremely positive about their experiences, valuing the non-judgmental, strengths-based and empowering aspects of peer approaches. The few participants who had a good understanding of the relationships between their drug use, drug treatment and mental health problems had all engaged with drug user organisation resources relating to comorbidity.

1.3 Results from service provider interviews

Interviews with drug and alcohol and mental health professionals and with staff from referral, support and advocacy services (particularly drug user organisations) were conducted in the same sites from which service users were recruited. Many of the issues raised by providers echoed or paralleled the views of service users. Additional issues raised by service providers included:

- difficulties in the diagnosis of mental health disorders, such as anxiety and depression, within a drug treatment setting

- lack of confidence in the management of anxiety and depression within drug treatment services

- acknowledgment that people with drug and mental health disorders continue to 'fall between the cracks' of mental health and drug treatment services

- the need to foster a culture of willingness to work together between drug and mental health services

- the absence or limited provision of training for health professionals in dealing with co-occurring drug and mental health problems

- the lack of feedback from other services after referrals, making follow up and review of service user progress difficult

- the challenge of developing well-coordinated care to attract service users into treatment

- the potential for primary health care professionals, particularly GPs, to act as coordinators of care for service users with complex needs that include drug and mental health disorders

- a lack of resources and restrictions on the way that funding is allocated to treatment services.

1.4   Barriers to treatment

Barriers to effective drug treatment identified by service users and service providers included:

- the stigma associated with both drug use and mental health, resulting in service users denying symptoms or feeling unable to seek treatment

- the impact of service user anxiety and depression symptoms on self-motivation and help-seeking behaviour

- the lack of holistic or comprehensive services, forcing service users to access and work with many different services and providers, often in a variety of locations

- complex vulnerabilities such as physical health problems, family issues, relationship breakdown, debt, criminal justice problems and unstable accommodation impacting on treatment success

- lack of resources within drug treatment settings, particularly for access to mental health services

- overly restrictive entry requirements for drug treatment programs for service users with co-occurring drug and mental health problems.

1.5   Conclusions and recommendations

Findings from both the service user and service provider interviews show that people with a history of illicit drug use and co-occurring anxiety or depression are still not well served by drug and alcohol or mental health services. Participant lives (and treatment outcomes) were complicated by issues such as the restrictive delivery of drug treatment, physical health problems, family breakdown, debt, poverty, housing or dealing with the criminal justice system.

The findings of the study suggest an urgent need for a national, conjoint mental health, alcohol and drug health system to be developed with the following characteristics:

- integrate treatment with the public health model using a range of strategies

- recognition that illicit drug users, as service users, have the same rights as any other consumer within the Australian health system

- instigating low threshold, easy access for service users with complex needs

- integrating and co-locating a range of treatment options within services

- adequately resourcing and training staff in co-occurring drug and mental health problems

- encouraging and appropriately resourcing drug user organisations and consumer advocacy/participation within treatment services.

Such a system would bring together, for the benefit of the service user, the sensible and practical elements of the currently separated drug and mental health systems. It would allow for a mix of sequential, parallel and integrated approaches to treatment, while continuing to recognise the differences and specialist elements contained in each of these sectors.

Detailed recommendations from the project can be found in Chapter 7.

Chapter 2:
Introduction

Considerable attention has been focused on co-occurring drug and mental health problems in Australia from service provider, policy and strategic perspectives, with much of this work coordinated under the auspices of the National Comorbidity Project (e.g. Siggins Miller Consultants, 2003; Teesson & Burns, 2001; Teesson & Proudfoot, 2003).

Less attention has been paid to the experiences of people living with both drug and mental health problems or to the consumers of drug treatment and mental health services with a view to matching service delivery to consumer needs (Gowing, Proudfoot, Henry-Edwards & Teesson, 2001).

2.1 Scope of the problem

From the literature, it is clear that people who are dependent on illicit drugs and consumers of drug treatment services are significantly more likely to suffer from mood and affective disorders, particularly anxiety and depression, than the general population. It is generally accepted that rates of substance use are higher among those with mental health problems compared to those without, and that people who use illicit drugs are more likely to experience mental health problems than non-users (NSW Health, 2000). As Hall, Lynskey & Teesson (2001) put it: "comorbidity is the rule rather than the exception with mental disorders" (p. 15).

Data from the National Survey of Mental Health and Wellbeing (Hall, Teesson, Lynskey, & Degenhardt, 1999; Teesson, Hall, Lynskey & Degenhardt, 2000) suggests that:

- In a given year, 2.2% of Australians meet criteria for dependence or harmful use of a controlled substance (a drug use disorder).
- Of those classed with a drug use disorder, nearly two out of three meet criteria for a mental health problem (most commonly anxiety or depression), compared to around one in nine of those without a drug use disorder.

Australian rates of mental health comorbidity among people who are drug dependent reflect rates found internationally, although there is considerable variation between countries. Among people classed as drug dependent in five Western countries, rates of comorbid mood and anxiety disorders ranged between 30% and 56% (Merikangas, Mehta, Molnar, Walters, Swendsen, Aguilar-Gaziola et al., 1998).

Rates of comorbidity among those presenting for treatment are generally higher than those found in the general population. This trend is borne out by a study of 45,000 general practice patients across Australia (Hickie, Koschera, Davenport, Naismith & Scott, 2001), which found that 12% of patients met criteria for comorbidity (any psychological problem with alcohol or other substance misuse). Other studies of Australians who use illicit drugs or seek drug treatment find predictably high rates of mental health comorbidity. A recent study of entrants to treatment for heroin dependence in Sydney found that 26% qualified for a diagnosis of major depressive disorder (Teesson, Havard, Fairbairn, Ross, Lynskey & Darke, 2005). A broader study of 825 heroin users entering treatment in Sydney, Adelaide and Melbourne found that 49% reported severe psychological distress, 28% met criteria for major depression and 37%

had attempted suicide (Ross, Teesson, Darke, Lynskey, Ali, Ritter et al., 2005). A study of methadone clients found that 76% met International Classification of Diseases (ICD-10) criteria for a psychiatric disorder within the previous 12 months (Callaly, Trauer, Munro & Whelan, 2001). Anxiety and affective disorders (such as depression) were the most commonly reported problems. A study of regular amphetamine users found that nearly half had been diagnosed with a mental health problem (Baker, Lee, Claire, Lewin, Grant, Pohlman et al., 2004).

People who use illicit drugs (especially those presenting for treatment) tend to show particularly high levels of mental health comorbidity. The most common mental health problems experienced by people who use illicit drugs are anxiety and mood disorders.

2.2 Treatment issues

Comorbidity poses particular problems for consumers seeking treatment for drug dependence or mental health problems, and for health professionals in both the drug and alcohol and mental health sectors. Unsurprisingly, comorbid conditions are more difficult to treat and manage than single drug or mental health conditions, and are associated with poorer treatment outcomes for consumers (Greig, Baker, Lewin, Webster & Carr, 2006; Hall, 1996; Siegfried, 1998).

There is little research directly addressing the experience of co-occurring drug and mental health problems from a consumer rather than service provider perspective. What research there is (Davis, 2003; Manns, 2003; Treloar, Abelson, Cao, Brener, Kippax, Schultz et al., 2004; Wright, Klee & Reid, 1999) suggests the following issues are of concern and interest to service users:

- access and equity in service provision
- suitability of drug and mental health treatments for people living with drug and mental health problems
- consultation with and support from service providers in making treatment decisions
- management of complicating factors such as relationships, housing, poverty, crime and physical comorbidities
- coping with stigma and discrimination.

There are a number of reviews and evaluations of 'best practice' in drug treatment focusing on the experiences and needs of health professionals (e.g. Holmwood, 2003; Jenner, 2002; Kavanagh, Greenaway, Jenner, Saunders, White, Sorban et al., 2000; Kavanagh, 2001; McNamara, 2003; Robinson, Gomes, Pennebaker, Quigley, & Bennetts, 2001; Siegfried, Ferguson, Cleary, Walter & Rey, 1999; Siggins Miller Consultants, 2003). This work suggests that service providers have the following main concerns about the treatment of co-occurring drug and mental health problems:

- the adequacy of training in comorbidity
- the adequacy of support services for comorbid clients
- problems with interagency support and communication

- tensions between treatment philosophies and models of care
- establishing effective therapeutic relationships with stigmatised and disorganised consumers.

Early reviews suggested that integrated models of treatment which provide a range of therapeutic options for drug treatment, mental health support and other complex vulnerabilities, and which treat co-occurring conditions simultaneously, were likely to be more effective in handling the challenges posed by co-occurring drug and mental health problems (e.g. Drake, Mercer-McFadden, Mueser, McHugo & Bond, 1998; Siggins Miller Consultants, 2003). Integrated approaches to treatment emphasise trust and understanding rather than confrontation and criticism, focus on harm reduction rather than abstinence, and accept the need for long-term support rather than rapid withdrawal and short-term treatment. Integrated approaches are often assumed to be preferable because they are supposed to be easier to access and attend by consumers, are designed to deal with the mutual influences of drug use and mental health problems, and they allow for the monitoring of both conditions at the same time by the same treatment team.

Recent reviews suggest there is no clear evidence that integrated treatment approaches are superior to sequential or parallel approaches (Donald, Dower & Kavanagh, 2005; Jeffrey, Ley, McLaren & Siegfried, 2004). One review suggests that while treating substance use disorders may help those with common mental health problems to achieve remission, treating mental health problems does not necessarily help in reducing problematic substance use (Proudfoot, Teesson, Brewin & Gournay, 2003). These mixed findings may, of course, reflect the difficulty of generating a unified approach to treatment when the experience of comorbidity is so diverse, rather than a failure of specialist services and treatment approaches (Davis, 2003).

What seems clear is that whatever the style of drug treatment service, providers need to be able to accommodate multiple comorbidities among drug treatment service users with substantial variation and fluctuation over time. As Kavanagh (2001) has noted, it may well be that some service users will benefit from sequential treatments, while others will benefit from parallel or integrated approaches, and services need to be able to implement this kind of flexibility in response to comorbidity. Bearing this in mind, it is likely that integrated services are better suited to providing flexible treatment arrangements for consumers than separated drug and mental health services (Siegfried, 1998).

2.3   Background to the project

The previous study of *Barriers and Incentives to Treatment for Illicit Drug Users* (Treloar et al., 2004) suggested that mental health comorbidities and other complex vulnerabilities (such as housing, poverty, physical illness or criminal justice issues) were of particular concern to those considering or participating in formal drug treatment but these issues were not well incorporated into treatment systems.

Because treatment services tend to be assessed by measures that reflect clinical priorities and not necessarily those of consumers (Gowing et al., 2001), the current study set out to explore and document the experiences of drug treatment service users, using their

experiences as the central focus of the study. Although there may indeed be 'endemic limitations [in] conducting research with people with co-occurring mental illness and substance use disorder' (Siggins Miller Consultants, 2003, p.21), we decided not to discount consumer perspectives because of a perception that people with drug and mental health problems lead chaotic and disorganised lives, or may be too ill or impaired to participate in research. This perception only reinforces the stigmatisation of people living with drug and mental health issues, and makes it less likely that service assessments and evaluations of current treatment practice will deliver outcomes of benefit to consumers. As Manns (2003) warns: 'Responses that don't include consumers and carers will fail' (p. 143).

The project also deliberately set out to explore the experience of the most common, high prevalence mental health conditions among drug treatment consumers, namely anxiety and depression. This was in response to the recognition that 'discussions of service delivery often focus on people with psychoses and substance use, usually cannabis use; those whose disorders cause obvious need for treatment, and those who the community cannot help but notice. Individuals with the more common depressive, anxiety and alcohol use disorders are often overlooked' (Proudfoot et al., 2003, p. 121).

The project therefore aimed to place consumer perspectives in the foreground, while acknowledging the difficulties that service providers face in dealing with comorbidity and complex vulnerabilities. It also aimed to shed light on the ways that common mental health conditions are managed within drug treatment services, and by consumers themselves.

2.4   Notes on terminology

During the lifetime of this project, the terminology related to comorbid drug and mental health conditions has shifted and changed. This may reflect a lack of certainty within the drug and mental health fields over aetiology, appropriate terminology to use with consumers, or different ways to describe different types of comorbidity. After discovering that consumers were very unfamiliar with terms such as comorbidity and dual diagnosis during the course of interviewing, the research team adopted more neutral terminology to refer to comorbid conditions. Therefore, in general we refer to 'co-occurring drug and mental health problems' rather than comorbidity.

Throughout this report, we generally refer to people who use drug treatment services as 'service users' or 'consumers'. This partly reflects our belief that those accessing drug treatment services should be seen as consumers of health care with the same rights as any other consumer of health services. We have tried to avoid terms such as 'illicit drug users' or 'injecting drug users' because although all the service users who were interviewed had experience of illicit or injecting drug use, many had stopped or were reducing their drug use while engaged in treatment. We also have tended to avoid the terms 'client' or 'patient' as we believe these terms suggest passivity and, wherever possible, in this report we have tried to explore how service users actively engage in or negotiate their drug treatment when conditions allow them to do so.

Health conditions and the social, legal and financial issues associated with problematic drug use can exacerbate the relationship between drug and mental health problems, and

complicate the individual's experience of treatment. We have termed this range of factors 'complex vulnerabilities'.

In general, we have used the terms 'substitution treatment' or 'substitution pharmacotherapy' to refer to forms of drug treatment where an opioid drug (like methadone or buprenorphine) is prescribed with the intention of substituting for or replacing illicit opioid use, i.e. heroin.

Chapter 3:
Methodology

The project employed five components to explore the challenges experienced by people with co-occurring mental health and illicit drug problems when accessing drug treatment:

- literature review
- Expert Reference Network
- interviews with drug treatment service users
- interviews with drug treatment, mental health and other service providers
- key informant workshop.

Wherever possible, the study design conformed to or incorporated the Australian Injecting and Illicit Drug Users League's guidelines on conducting ethical research with injecting or illicit drug users (AIVL, 2002). The study was also reviewed and approved by the human research ethics committees of the University of New South Wales, the South East Sydney Area Health Service, the Mid Western Area Health Service (NSW), and the Prince Charles Hospital Health Service District (Brisbane). The Western Australian Drug and Alcohol Office also reviewed and approved the study.

3.1   Literature review

At the start of the project, a literature review was conducted, looking at existing research and publications concerned with drug treatment and mental health comorbidity. The review focused on the Australian literature, but also drew upon key international work on drug treatment and mental health, where appropriate. In particular, the review targeted research that had investigated the particular issues faced by former or current injecting drug users, those who had been diagnosed with common mental health problems such as anxiety or depression, and any research or evaluation that had employed qualitative methods to explore the experiences of those seeking or engaging in treatment for illicit drugs.

The initial literature review was included in a discussion document that identified key issues and questions for the project. The discussion document was circulated to the project Expert Reference Network for comment, and was used to inform the development of the service user and service provider interview schedules.

3.2   Expert Reference Network

The project management committee (LMS Consulting, AIVL and NCHSR) invited experts on drug treatment, mental health and related issues to act as a 'virtual' reference network for the project. The reference network was asked to comment on the preliminary literature review, to offer feedback on the project design, and to comment on preliminary findings and contribute to draft recommendations of the final report. Seventeen experts agreed to join the reference group, with backgrounds in academic research, clinical practice, government policy, consumer advocacy and community engagement (including drug user representatives). A number of reference network members participated in the key informant workshop towards the end of the project. See Appendix A for the list of Expert Reference Network members.

3.3   Service user interviews

The literature review and discussion document informed the development of a schedule for semi-structured interviews with users of drug treatment services (see Appendix B). Topics of the interviews included: illicit drug use history, history and experience of drug treatment, mental health background and treatment, self-management strategies, experience of complex vulnerabilities, and barriers and incentives to treatment.

Seventy-seven users of drug treatment services were recruited from four locations: Sydney (n=21), Bathurst (n=16), Brisbane (n=20), and Perth (n=20). These sites were chosen because they: represented a range of metropolitan and regional areas; have a variety of drug treatment and mental health services; and were successfully used for recruitment in the previous *Barriers and Incentives to Treatment* study (Treloar et al., 2004).

Service user participants were recruited between December 2004 and June 2005. In each site, a convenience sample was recruited using a range of strategies including advertising in local drug treatment centres, advertising in drug user organisations (where available), peer recruitment and word-of-mouth.

All service user participants were at least 18 years of age, could comprehend and speak English, had a history of illicit opiate or stimulant use, had experience of formal drug treatment in the past two years, and had been diagnosed with or received treatment for anxiety, depression or a similar mood disorder in the past two years. Other mental health conditions were not considered a barrier to participation unless they were currently untreated or unmanaged or were judged to impair the participant's ability to consent or participate.

3.3.1   Peer recruitment

The peer recruitment method employed in this project was overseen by the Australian Injecting and Illicit Drug Users League (AIVL). In each site, two peers with experience of illicit drug use, knowledge of drug treatment, and a range of local contacts and expertise were employed to recruit eligible interviewees through their drug user and ex-user networks. The use of peer recruiters facilitated access to potentially hard-to-reach networks of illicit drug users, and provided a way for current and ex-drug users and those in treatment to find out about the project without first having to be identified to the research team.

The peer recruitment positions were advertised through the NSW Users and AIDS Association (NUAA) in Sydney, the Western Australian Substance Users Association (WASUA) in Perth, the Queensland Alcohol and Drug Research and Education Centre (QADREC) in Brisbane, and through contacts of NCHSR and AIVL in Bathurst. The peer recruiters were jointly interviewed and appointed by AIVL and NCHSR staff.

The peer recruiters received in-depth training to familiarise them with the project's background and goals, and to identify recruitment strategies and barriers to recruitment. The recruiters were also encouraged to monitor potential health and safety issues. Peer recruiters were trained to screen all potential interviewees using a checklist developed by NCHSR and AIVL (see Appendix C). The checklist allowed recruiters to identify

eligible participants, focusing on the potential participant's ability to understand, communicate and give or withhold consent, as well as their drug use, drug treatment and mental health histories.

Peer recruiters were provided with a Peer Recruiter's Manual that covered the majority of issues that could arise during the recruitment process, information on the research process, drug treatment, blood-borne viruses and relevant support contacts. To assist them in their work, peer recruiters were provided with a mobile phone (when required), and a pack containing the Peer Recruiter's Manual, pens, paper and other stationery items. Ongoing support and supervision was provided to the peer recruiters by the AIVL project worker. Contact with peer recruiters was maintained by phone, email and mobile phone text messaging. At the end of the process, peer recruiters were sent a certificate that evidenced their work and the skills they had utilised.

During the recruitment phase of the project, peer recruiters identified potential participants through their networks, screened all potential participants, and then invited eligible participants to take part in an interview with one of the NCHSR researchers. Peer recruiters arranged interview times with participants and informed the research team and the AIVL project worker of their appointments. The recruiters also reminded participants of appointments to make sure they knew when and where their interview was taking place.

3.3.2   Interview process

Interviews with service users were conducted by NCHSR researchers, following the schedule given in Appendix B. Interviews were conducted in locations that were judged to be safe, private and accessible for both participants and researchers. In Sydney and Perth, most interviews were conducted in rooms at drug user organisation offices (i.e. NUAA and WASUA). In Sydney, a small number of interviews were also conducted at the Hepatitis C Council of NSW. In Bathurst, interviews were conducted in a private room near the main pharmacotherapy dosing centre at Bathurst Base Hospital. In Brisbane, interviews were conducted in private rooms at the Biala Methadone Clinic, at QADREC, and at the Fortitude Valley office of the Queensland Injectors Health Network (QuIHN).

Before commencing an interview, the researcher provided the participant with a consent form and project information sheet (see example in Appendix D) and confirmed that the participant understood the nature of the study and was willing to proceed. The participant and researcher then completed the consent form. Interviews were conducted in an informal, semi-structured, conversational manner and were recorded on audio tape. Participants were free to terminate the interview at any time. Interviews lasted between 15 minutes and one hour. On completion of the interview, each participant received $20 expenses for their time and for any incurred costs.

3.3.3   Data management and analysis

All interviews were transcribed verbatim and identifying names and details were removed and pseudonyms applied. A coding framework was developed to capture the major themes and issues contained within the material. The framework reflected issues identified in the literature review, project management team discussions, a selection

of transcripts read by the research team, and through observations made during the recruitment and interviewing process (see Appendix E). Every interview transcript was coded independently by two members of the NCHSR research team. Coding discrepancies and disagreements were resolved through discussion. Once coding was completed, the coded transcripts were entered into NVivo qualitative data analysis software for storage, retrieval and analysis.

Analysis of the service user interviews was informed by the research team's expertise in thematic analysis, grounded theory (Glaser & Strauss, 1967) and discourse analysis (Potter & Wetherell, 1987). The coding framework was used as the point of departure for analysis. Analysis proceeded by selecting particular topics of interest from the coding framework, then reading, organising and discussing all the material that was contained within a particular code, looking for consistencies, commonalities and points of difference. This resulted in a more detailed breakdown of the code into subthemes and key experiences, identifying interview sections and specific quotations for each subtheme. This formed the basis for much of the analysis presented in this report. As analysis proceeded, there was some cycling between the targeting of particular topics of interest (driven by the project aims, literature review and coding frame), identifying new or emergent issues through reading and re-reading transcripts, and focusing on particular participants' accounts and experiences to 'test out' emerging analyses and to produce case studies. Preliminary analyses were contrasted against the existing research literature, looking for agreement with existing research findings, points of disagreement and new insights.

3.4   Service provider interviews

The literature review, discussion document, and preliminary observations from service user interviews were used to inform the development of the service provider interview schedule (see Appendix F). Topics of interviews included: description of current role, responsibilities and type of service provision, contact with service users experiencing both drug and mental health problems, particular challenges posed by these service users, approaches to comorbidity within the participant's service, ideal models of care and support for service users experiencing comorbidity, and barriers and incentives to treatment.

Eighteen service providers were recruited from the same areas targeted in the service user arm of the study: Sydney (n=7), Bathurst (n=3), Brisbane (n=3) and Perth (n=5). For recruitment purposes, drug treatment, mental health and allied support services, as well as drug user and peer organisations were identified in each area. Methadone prescribers outside of drug treatment services (i.e. specialist GPs), referral agencies, policymakers and consumer advocates were also identified. Providers were sent a letter inviting them to participate in the study, and a project information sheet and consent form. Providers were asked to contact the research team at NCHSR to arrange a confidential interview and to return the signed consent form by post or fax.

Interviews were primarily conducted over the telephone, although some participants in Sydney elected to have face-to-face interviews. Interviews were conducted by a NCHSR researcher in an informal, semi-structured, conversational manner and were

recorded on audio tape. Participants were free to terminate the interview at any time. Interviews lasted between 30 minutes and one hour. Service providers did not receive expenses for participation.

3.4.1   Data management and analysis

All interviews were transcribed verbatim and identifying names and details were removed. Because there was a smaller number of service provider interviews compared with the number of service user interviews, analysis of the service provider accounts was more reliant on a grounded theory approach (Glaser & Strauss, 1967). Transcripts were read and re-read by one member of the NCHSR research team, looking for patterns, consistencies, and points of difference. The analysis was developed to identify any degree of consensus within the material as well as idiosyncratic or individual points of view. This identified topics and experiences of particular interest to service providers in relation to the treatment of people with both drug and mental health problems.

The focus of this project was to be the experience of service users with both substance use and mental health problems. To that end, the analysis of interviews with service providers served as a "check" step for the findings from the service user interviews. The data were read to explore the degree of correspondence between service user and provider perspectives.

However, the service provider findings should not be regarded as a complete exploration of the professional field. A relatively small number of participants (n=18) were recruited from the drug and alcohol field, mental health services, drug user organisations and those who specialise in or have responsibility for dual diagnosis services. Hence, we cannot claim to have reached saturation with these data.

3.5   Key informant workshop

A key informant workshop was held in Sydney in February 2006. The workshop provided a forum to discuss preliminary findings from the service user and service provider arms of the study, identify challenges and implications, and make recommendations for the improvement of care, support and treatment of those with both illicit drug and mental health problems.

Thirty people attended the workshop, including the project management team, representatives from the Australian Government Department of Health and Ageing, academic and clinical researchers, drug user organisation representatives, drug treatment specialists, mental health practitioners, consumer advocates and representatives of general practitioners. Potential participants were identified through the project management team's network of contacts and the Expert Reference Network, and were invited to attend by letter or email. Some service providers who had provided advice or assistance during service user recruitment, or who had been interviewed for the service provider arm of the study, were also invited to attend.

During the workshop participants shared information about the study and its preliminary findings, and gained an appreciation of the issues arising from the study.

The implications of the study for future service delivery and support systems were discussed, and a number of broad policy recommendations were identified by workshop participants. The recommendations were aimed at enabling better synergies between services, support systems and the needs of those seeking help for both illicit drug and mental health problems. The project management team used the workshop outcomes as a guide in formulating the recommendations that appear in this report.

3.6   Description of service user participants

Seventy-seven participants were recruited for the service user arm of the study. Details of the participants' demographics and a breakdown by recruitment site are given in Table 1. The mean age of participants was 37 years and relatively equal numbers of men and women were recruited overall, although women were over-represented in Sydney and under-represented in Bathurst. The vast majority of participants were Australian-born (82%), and a relatively high proportion reported Aboriginal or Torres Strait Islander heritage (16%), particularly among those recruited from the Bathurst area. Participants recruited from Perth were most likely to report being born overseas.

Perhaps unsurprisingly for a drug treatment population, the vast majority of participants reported living on government welfare or benefits (88%) and only 12% of the sample was employed at the time of the study. Participants from Brisbane were most likely to report paid employment. The majority of participants lived in private rental accommodation (57%), although relatively high proportions lived in public housing (particularly in Bathurst) and temporary accommodation such as boarding houses, hostels or refuges (notably in Sydney). Participants from Brisbane and Perth were more likely to report living in private rental accommodation than those recruited from other locations. Perhaps surprisingly, nearly 40% of the sample had attended some form of post-compulsory education, i.e. further or higher education. Participants from Bathurst were the least likely to report participation in post-compulsory education.

Table 2 shows a breakdown of service user participants by recruitment site, drug use history, drug treatment history, mental health diagnosis and hepatitis C status. Nearly all the participants had a history of using illicit opiates (94%), most commonly heroin. Three-quarters of service users (75%) also reported using illicit stimulants, notably amphetamines, crystal methamphetamine, ecstasy or cocaine. The vast majority of participants (91%) had tried or were receiving substitution pharmacotherapy (primarily methadone or buprenorphine) at the time of the study. Over two-thirds (69%) had engaged in other forms of drug treatment, e.g. counselling, detoxification, residential rehabilitation, abstinence-based programs. Nearly all of the participants (95%) had been diagnosed with or been treated for depression in the two years prior to the study or were still coping with depression at the time they were interviewed. More than one-quarter of participants (29%) had been diagnosed with and had experience of anxiety. The majority of participants (71%) said that they had hepatitis C.

Table 1:   Service user participants by site and demographic criteria

	Sydney	Bathurst	Brisbane	Perth	Total (% of sample)
Gender					
Male	7	11	12	9	39 (51%)
Female	14	5	8	11	38 (49%)
Age					
18-25 years	3	3	2	1	9 (12%)
26-40 years	11	10	12	14	47 (61%)
>40 years	7	3	6	5	21 (27%)
Country of birth					
Australia	18	15	17	13	63 (82%)
Other	3	1	3	7	14 (18%)
Aboriginal or Torres Strait Islander heritage	4	5	1	2	12 (16%)
Education					
Up to Year 12 (high school)	12	13	11	11	47 (61%)
Technical and Further Education (TAFE)	2	2	2	1	7 (9%)
University	7	1	7	8	23 (30%)
Source of income					
Welfare/benefits	20	16	15	17	68 (88%)
Employment	1	-	5	3	9 (12%)
Type of accommodation					
Owner occupier	1	-	-	1	2 (3%)
Private rental	7	8	12	17	44 (57%)
Public housing	7	8	5	1	21 (27%)
Boarding house/ hostel/refuge	5	-	2	1	8 (10%)
Homeless	1	-	1	-	2 (3%)
Total (% of sample)	**21 (27%)**	**16 (21%)**	**20 (26%)**	**20 (26%)**	**77 (100%)**

Table 2:   Service user participants by site and drug use history, treatment history, mental health diagnosis and hepatitis C status

	Sydney	Bathurst	Brisbane	Perth	Total (% of sample)
Illicit drug use history					
Opiate use*	20	15	18	19	72 (94%)
Stimulant use*	15	10	16	17	58 (75%)
Drug treatment history					
Substitution pharmacotherapy*	20	15	17	18	70 (91%)
Other drug treatment*	18	8	10	17	53 (69%)
No treatment (seeking/ considering)	-	1	1	-	2 (3%)
Mental health diagnosis					
Depression*	18	16	20	19	73 (95%)
Anxiety*	7	2	8	5	22 (29%)
Hepatitis C (HCV) status					
HCV-positive	17	15	14	9	55 (71%)
HCV-negative /cleared/ unknown	4	1	6	11	22 (29%)
Total (% of sample)	**21 (27%)**	**16 (21%)**	**20 (26%)**	**20 (26%)**	**77 (100%)**

* Not mutually exclusive categories

3.7   Description of service provider participants

Eighteen participants were recruited for the service provider arm of the study. Table 3 gives a breakdown of service provider participants by recruitment site and type of service. The majority of service provider participants were recruited from Sydney (39%) and Perth (28%). There were difficulties in recruiting participants from Bathurst and Brisbane. The majority of participants (56%) were employed by drug and alcohol treatment services (public and private), although some of these participants were employed as counsellors, i.e. mental health professionals.

Table 3:   Service provider participants by site and type of service

	Sydney	Bathurst	Brisbane	Perth	Total (%)
Drug or alcohol treatment service	5	2	2	1	10 (56%)
Drug user organisation	1	-	1	2	4 (22%)
Mental health service	-	1	-	1	2 (11%)
General practitioner	1	-	-	-	1 (6%)
Non-governmental organisation/other service	-	-	-	1	1 (6%)
Total (%)	**7 (39%)**	**3 (17%)**	**3 (17%)**	**5 (28%)**	**18 (100%)**

Chapter 4:
Service user interviews

This chapter presents findings from interviews with consumers of drug treatment services. The material presented here pays particular attention to the ways in which having a common mental health problem, such as anxiety or depression, was understood and managed by participants and within services. Attention is also paid to the ways that mental health problems affected service users' lives and their experience of drug treatment.

4.1   Accounting for mental health problems

Participants were asked to describe the background to their mental health problems, and how they understood the relationship between their illicit drug use and their mental health. This sometimes meant that participants explained how they made sense of a clinical diagnosis and related that information to their own experience. Some participants expressed multiple opinions on and representations of mental health problems – reflecting the different ways in which people try to make sense of their experiences. However, many participants struggled to describe the background to and evolution of their mental health problems.

As the project progressed, it became obvious to the research team that while drug treatment service users could often provide rich and detailed stories of their illicit drug use and experiences of drug treatment, they were much less able to describe their mental health background or put into context their attempts to seek assistance for mental health problems. Within the project team, it was suggested that while those who use illicit drugs or identify as 'users' may develop personal narratives or biographies that account for drug use, the continuing stigma of using illicit drugs, and the additional stigma of being seen as 'mentally ill', may prevent the acknowledgment of mental health difficulties. In particular, it was suggested that managing the daily challenges of being drug dependent may overshadow the experience of mental health problems for consumers. It was also suggested that mental health diagnoses may be poorly explained to service users by treatment providers. These issues are illustrated below:

> 'I sort of don't normally consider myself having mental health problems, although, I know that I do 'cause I've been to see doctors about it, you know but it's not, not something that I take on as part of my identity.' (#38, male)

> 'I sort of didn't worry about it [anxiety] because it was the lifestyle sort of [it] just was all part of it, [it] didn't really matter at the time, it was only once I decided to pursue a different track – that's when it has become an issue. Previous to that it didn't matter because I was being irresponsible, who gives a shit? It's just like as long as I was having fun and you know I wasn't hurting anyone, it didn't matter.' (#1, female)

> '…just been talking to my doctor and telling her how I felt, oh well she sort of sat down and was like this and this and that and I said 'yeah' and she said 'you're depressed' and just talking…[I] didn't take like when people were talking to me I wasn't really listening. I couldn't take anything in.' (#27, female)

However, despite these difficulties in acknowledging or talking about their mental health problems, participants did give varied accounts of how they understood and experienced anxiety and depression. Some participants believed their mental health difficulties originated in childhood or family experiences, while others talked about different factors, including personality, stressful life events (such as bereavement) or contextual triggers. Drug use, especially dependent, problematic or harmful use, was often implicated in the emergence or intensification of a mental health issue. Many participants gave more than one reason for the emergence of anxiety or depression.

4.1.1 Drug use leading to mental health problems

Many participants believed that illicit drug use had led to their problems with anxiety or depression. Dependence on illicit drugs, notably heroin, was seen to adversely affect mood, but it was being drawn into a drug dependent 'lifestyle', characterised by crime, debt, risk and poor health, that was most closely associated with feelings of hopelessness and depression. The secrecy and stigma of using illicit drugs such as heroin was seen to exacerbate the likelihood of depression:

> '…it's mostly been depression like, to do with gaol and drugs, like it hasn't been something I had, like I don't think I would have experienced it without being on drugs, I would have missed on like even knowing about that you know.' (#15, male)

> 'I don't know whether I choose to or whether there is a fear, I have sort of chosen to use [heroin] recently and um... and I have had like a lack of motivation or inspiration to sort of find the meaning to live apart from just basically getting through each day to survive.' (#47, male)

> '…ultimately the problem is that you can't afford to use if using is um, interfering with your social and the rest of your life because it is so stigmatised, if all those other negative consequences of drug use are there then the only harm in... the result of that is also going to be all the symptoms and that's depression…' (#45, male)

For the smaller number of participants whose main drug problem had been with stimulants, particularly amphetamines, some also reported that their mental health problems resulted from drug dependence or a drug-using 'lifestyle'. Excessive or dependent stimulant use was also reported as leading to erratic behaviour, anxiety, paranoia and feeling out of control:

> '…speed's been the most damage, that was definitely, definitely a huge, huge turning point in my life in 1996. I lost everything, I mean I was earning eighty-six thousand a year, I had a one hundred and six thousand dollar car, and um all of that went down the gurgler, lost a girlfriend and ah ended up living on the streets in the end, that's how bad it got… the depression is definitely related to drug use.' (#54, male)

> 'I've used so much speed, it's given me paranoia and anxiety… [edit] …using the speed for a long time it does set you, like I don't know but people loop out

and they think people, like, coppers are across the road in trees and looking at them and, a lot of stuff it's, anyone who says that the drug hasn't affected the way they think or the way they act, it's not true. 'Cause it does.' (#43, male)

'There were times when I was really bloody crazy from the drugs.' (#3, female)

4.1.2   Drug use as a way to cope with mental health problems

Participants described how they had turned to illicit drugs to cope with, manage or mask the symptoms of anxiety or depression. 'Self-medicating' to deal with unpleasant feelings or circumstances was recognised as problematic in the long term, but participants described how illicit drug use could sometimes be the easiest, most accessible or effective way to cope with the adverse effects of anxiety or depression in the short term:

> 'I didn't start to use [heroin] until well into being 35... and it was an accident – I actually thought I was snorting a line of cocaine and um... my naivety – but at the time I had really bad depression and I think I would have put anything in my nose and um I just thought "god that feels better, whatever it is" and quickly tried to buy some more... Yeah so that's how it came about 'cause I was already in a depressed state when that started and um... of course that made the problem better for a little while and then that became the problem in itself…' (#42, female)

> '…[heroin] was the most effective thing I ever had for the anxiety, I was very anxious at the time too, I was a bit of mess and it was remarkable, absolutely remarkable.' (#12, female)

> 'I think that I'd been self-medicating for a long time and just graduated up the drug vine. Yes, I think the depression was there first and the drugs and that would have helped initially and given me the power to socialise. Then they started making things worse.' (#60, male)

> 'I realise that drug use isn't because I like drugs, obviously it was a big crack at me self-esteem and you know I find that when I don't use illicit drugs or legal drugs, prescribed ones that, you know, that crack appears and I become depressed…' (#56, male)

4.1.3   Challenging life circumstances leading to drug and mental health problems

A common theme among the service user accounts was that of difficult or stressful circumstances leading to drug and mental health problems. This could involve family or childhood difficulties, breakdowns in relationships, work-related stress and coping with physical illness. Depression was described as resulting from ongoing stress and illicit drugs were described as a way to escape from difficult situations or to cope with a mental health problem (as in 4.1.2 above).

Participants frequently thought that their problems with depression or anxiety had originated in childhood, because of a family history of mental health problems, the relationship with their parents or difficult family and social conditions:

'I remember living underneath a manic depressive and what they're like and then when I became a teenager, I realised that I had similar things or that the feelings that I was evoking from deep, deep down inside were you know and, and um I don't know if it's 'cause um you know, we're from the same gene pool or if I, or if people just get it in life. But I got it and um yeah I mean I thought that, I looked to drugs to escape my depression 'cause I got it when I was about 13, 14. When I was 14 it really hit me, til I was about 16, 17 I was still struggling with it.' (#16, female)

'…my parents um didn't think that children should get big-headed. So, 'you're a lazy, good-for-nothing, know-all mongrel kid', when you're just a perfect child and doing everything you could possibly do to please them. So both my brother, my sister and I have all suffered from this incredibly low self-esteem which, I think, is one of the trademarks of anybody with a drug problem, is low self-esteem.' (#65, female)

'[I was] diagnosed with chronic depression um... was on antidepressants as a young child, I think that was due to first, started wetting the bed, right, and it was only when I was older and I looked up what tryptonol was, it was the first one I took and it was actually an antidepressant and then going through divorced parents and all that sort of thing, so for about 20 years I was on all sorts of antidepressants.' (#40, female)

Childhood abuse and neglect, both physical and psychological, was reported by a few participants. These traumatic experiences were seen as contributing to participants' later difficulties with depression, anxiety and drug use:

'I was two when they [my parents] separated so I don't… I remember a lot of that subconsciously but it's stayed in my head on some level. Then she [my mother] became involved with a man who became our stepfather for a while and I was sexually abused from six to twelve on a regular basis. I tried to disclose it to a number of people and eventually ended up being abused by one of the people that I trusted and disclosed to. I kept that fairly quiet for a long time and I learned to kind of develop other coping mechanisms and I guess that was part of the reason why I was such a candidate for getting into drug use at an early age, as a form of escapism.' (#71, male)

For other participants, it was stressful or challenging experiences in adulthood that had provided the trigger for illicit drug use and mental health difficulties. These stresses could include bereavement, unemployment, work-related stress and relationship breakdowns:

'…it started when I lost my daughter when I was 19, of course, and that's when I started with the drugs. And it sort of seems like every time I go through a really, really tough period in life, I'll go flying to the gear. Then, obviously, you get that depression stage – you always do. If anyone says they don't, I think it's bullshitting myself because that's why we take drugs – because we're not happy with our lives...' (#70, male)

'…hitting a very low point in my life where I was going through a relationship break-up, I was extremely depressed, my job was incredibly stressful and yeah, I found I was really depressed and really anxious all the time. That's when I started taking acid and speed which, when you're depressed, it sort of lifts you up and, you know, makes you all happy and you can go out and party all night and everything's sparkling and wonderful for a little while.' (#74, female)

4.2 Experiences of depression

The vast majority of participants (95%) had received a diagnosis of depression at some point during their lives. Those who had experienced depression in recent years reported a wide range of deleterious symptoms and effects. Symptoms included mood swings, feeling unable to deal with other people, disturbed sleep, tiredness, lacking motivation, having morbid thoughts, and being emotional and upset. Many participants reported not leaving home to avoid other people, not eating properly and not washing when they were depressed. These effects of depression, particularly feeling unable to deal with other people and lacking energy or motivation, could affect service users' ability to attend or participate in drug treatment:

'I mean, sometimes I get to a point where I just don't want to do anything, don't want to leave my flat, don't want to get out of bed, don't want to shower, don't want to eat, don't want to do anything at all. So to have to get up and get my dose is the last thing I want to do. But I find if that I just disguise myself and don't look anyone in the eye, just get there and get it and get home, so I do it really early in the morning.' (#67, male)

'I can't get out of bed, I can't be bothered having a shower, I can't get out of the house. I can't be bothered doing anything. The only thing that will actually get me going is I have to look after the kids, I can't not.' (#66, female)

Ten participants (13% of the service user sample) reported being sufficiently depressed that they had contemplated or tried to commit suicide:

'…after I had [my son], I got really bad postnatal depression. I went to two doctors, crying and said everything was terrible. And they said "just try to get your husband to help you more" – well that was their answer. This other woman said "Well, I had four children and I carried on". So I just used to think about how I could kill myself and my children without first having to see them dead or having them suffer in any way. And I just couldn't figure out any way that I could actually do it. But I took sleeping tablets and they made me vomit so I had to abandon that idea.' (#65, female)

'I have bouts where I just burst out crying or just feel really down and low. [I] think about suicide but I wouldn't go through with it like I would have tried in 2004, so I am just pulling myself together and staying clean and ah, on the Subutex [buprenorphine], taking the Subutex every day.' (#54, male)

4.3 Experiences of anxiety

Service users who had been diagnosed with anxiety (29% of the sample) described a range of symptoms and effects, some more debilitating than others. Participants most commonly described incapacitating anxiety or panic 'attacks', characterised by their hearts racing, sweating, feeling like it was difficult to breathe, extreme nervousness and panicked thoughts. A few participants described phobias (of being outdoors, in confined or unfamiliar spaces), and some described more generic symptoms such as fidgeting, forgetfulness or being disorganised.

> 'I used to weight lift and box. I could stand in a pub and I could punch my way out of that pub and not have any fear whatsoever. But have one attack, anxiety attack, and I will be cowering in the corner like a quivering little mouse that's been trapped there by a cat…' (#6, male)

> 'I've always been an anxious person I've always had – for quite some time – anxiety attacks. I didn't know what they were – I've always had that stuff where I'd get that sick feeling and my heart would be racing and I just would be really … yahh! You know? I was always one of those people who has been "highly-strung", you know, those kind of terms and stuff like that.' (#74, female)

> 'I still have those times if I'm not comfortable somewhere and it's not my own surroundings. I just feel like getting out and you're really, really tense and, before you know it, you're just saying "Ohh". I had one huge one [a panic attack] at the start of this year. That's when I saw the doctor again. And my doctor said to me "You know, it's only anxiety" like I shouldn't be… I just thought, "OK, maybe it was just the drug use when I was going through those other manic stages." So it kind of hit home, "Oh my God. OK, this could be something else".' (#75, female)

4.4 Understanding of clinical language for comorbidity

As the service user arm of the study developed, and the first set of interviews was reviewed, it became apparent that it was difficult to discuss concepts such as 'comorbidity' or 'dual diagnosis' directly with service users because they had little awareness or understanding of these terms. Different ways of talking about these issues within interviews were developed to address the relationships between drug use and mental health, whether both problems were addressed within treatment, and how service users understood their own problems. Often this meant that participants were asked to talk about drug use, drug treatment and mental health separately, and then were prompted to elaborate on whether they saw relationships between these different areas, how service providers had explained these relationships (if at all), and how they understood their own problems. If it had not come up before, participants were generally asked towards the end of the interview whether they had heard of the terms 'comorbidity' and 'dual diagnosis' and, if so, what the terms meant to them. Participants said that they had typically not heard of the terms and generally did not understand what they meant, although a few could guess that the

terms referred to having two, concurrent diagnoses ('Suffering from two different things', #60, male). 'Dual diagnosis' was slightly better recognised than 'comorbidity', perhaps reflecting its longer use in the drug treatment and mental health sectors:

> 'I've heard of dual diagnosis but I just can't remember like, in where or who said it but I've heard it.' (#16, female)

> 'Oh, dual diagnosis. I think I've heard that on TV.' (#19, female)

In attempting to guess what comorbidity or dual diagnosis might mean, service users generally evaluated the terms negatively (or with some humour), saying that they sounded clinical, pathological or related to death:

> 'I'm just assuming what it means, you know, co, co means like probably you're a part of some morbid thing.' (#19, female)

> 'No [I] haven't heard of comorbidity, sounds like, like two people wanting to go off and die together.' (#42, female)

> '…is that [comorbidity] to die with someone?' (#52, female)

> '…comorbidity is um after you're dead.' (#6, male)

> 'Is that [comorbidity] like when you're using more than one drug? No?' (#67, male)

> '…it sounds like two people dying together. What the fuck does that mean – comorbidity?' (#68, male)

Some thought that the terms were not used or explained to them because there was a perception among drug treatment providers that service users were unable to understand clinical terminology ('they might have thought I was too stupid because I'm a junkie', #12, male). Others thought that the lack of understanding of clinical terminology might be a barrier to service users' access to and participation in treatment:

> 'Yes, I think it scares a lot of people from asking or accessing or even just being involved or having anything to do with it [treatment] because it automatically tells them that it is, "you have got a problem and it's a serious fucking problem, it's a serious word". Mental, comorbid… to me it just sounds "shit, I don't need another label".' (#7, male)

However, a small number of participants did understand terms such as comorbidity or dual diagnosis. For one participant diagnosed with anxiety, he understood what comorbidity meant because he was one of the few participants who had accessed a specialist clinic for co-occurring drug and mental health problems. Another woman who had suffered from depression had the term dual diagnosis explained to her when she was referred to a specialist dual diagnosis program after being in gaol. Those who had participated in courses or activities designed to explain the relationships between drug

and mental health issues tended to have the best understanding of clinical terminology pertaining to comorbidity. The courses mentioned by participants were offered by drug user organisations and were only available in two of the four recruitment sites:

> 'It means that I have a drug problem and I have psychiatric issues as well. I've just completed a course through here [at my local drug user organisation] and it's specifically designed for dual diagnosis people.' (#72, female)

The publications of drug user organisations were singled out as one of the more obvious and effective ways that drug treatment service users could familiarise themselves with clinical language:

> 'Well dual diagnosis is familiar to me. Comorbidity I'd never heard of until we did this [the interview]... But most of that jargon people have no clue. The only ones, the only people that do have a bit of a, are people that read the magazines [from drug user organisations]. And everyone loves them and we don't get them.' (#22, female)

4.5 Accessing mental health support

Drug treatment service users sought or were offered support, advice or treatment regarding their mental health problems through a variety of sources. The three main avenues through which service users attempted to access mental health support were: through drug treatment services; mental health services; and through general practitioners. While some participants could point to positive experiences of gaining access to and then receiving appropriate mental health support (i.e. medication, counselling or therapy), many recalled that their problems were not taken seriously, that services were not available, and that gaining access to appropriate care was difficult (particularly when seen or identified as a 'drug user').

4.5.1 Mental health support through drug treatment services

As all the service user participants had accessed or planned to access drug treatment services, many of them had also attempted to get support or treatment for anxiety or depression through a drug treatment service. For a small number of participants, this had been a positive experience, with doctors and other support staff offering to discuss mental health and providing access to treatment and counselling:

> '…as I've got older and got more trust with my doctor, we have discussed more issues lately than before and he's relatively on the ball with how I am at the moment, he knows me pretty well. As earlier on in my experience in the methadone I was a bit more deceiving but now I'm sort of a bit more honest with my treatment…' (#44, male)

> 'Yeah, I'm finding more ways of dealing with [depression] by talking to my doctor about it because he's given me more suggestions and other ways to go about it so, yeah.' (#17, male)

However, the majority of service users reported that access to mental health support or treatment was poorly managed by drug treatment services. Methadone clinics (and the prescribing doctors that worked within them) were singled out as uninterested in or unable to deal with service users' problems with anxiety or depression:

> 'They just say, "Oh, you're not having a good time at the moment?". "No, I'm going through a bad time." I was homeless, my son and I were living in squats and everything last year and it was, "Oh, well, you'll survive, I'm sure; you're a tough one. Off you go, you'll be right. Do you want to up your dose a bit?". I've given up even bothering to ask any more because you know what they're going to come out with anyway is pointless. So I don't even bother to ask for help...' (#70, male)

> 'Sign Medicare, get your dose, all right and that's it.' (#10, female)

> 'How do you stop [private] prescribers from, you know if you said tomorrow, "why don't you offer these guys some real services and real counselling services, why not set up some counselling services here at your methadone clinic?". He'll laugh at you. He'd tell you about his overall expenses, too expensive. "I'd have to get in a counsellor".' (#8, male)

> '…if I did have something else wrong with me then I probably would go to another doctor, more so because he is very busy and to get it would require a couple of weeks on the waiting list but even if it was another physical ailment or if I did have mental health stuff come up I'd probably be inclined to pick a doctor with, that I felt had more experience in that, I really see him as the prescribing doctor which is kind of sad.' (#45, male)

In larger or more comprehensive drug treatment services, where substitution pharmacotherapies such as methadone were not the only available treatment option, service users could still face a range of problems in getting support for anxiety or depression. Lack of interest, expertise or resources, unsuitability of services on offer, and a focus on drug-related issues to the exclusion of mental health problems were some of the challenges service users faced:

> 'this guy here [at the drug treatment service]… went a bit cold when I asked about the anxiety and depression and all that, he said you need to refer to your GP' (#54, male)

> '…I do consider going to speak to someone else about [depression] because I know, with the services here, they're mainly for drug use. Right? Depression is a bit of a sideline from that – even though they're interconnected, it's a sideline and they don't have the resources as much as they'd need to address those issues with people, the clients. So I keep it mainly for a check-up every three months and then if I have something I want to talk about, they don't have the resources here really. I know they have groups available but I haven't looked into them.' (#76, female)

'There's no-one to talk to and when you're told that you, yeah you can see somebody in six weeks, that is of no help, at all. Because in six weeks, you've forgotten what the bloody problem was. If you don't get it there and then, you know sometimes you just need to be able, just being able to vent whatever it is that's building up, makes it go away. You know, just being able to share your problems or talk about what's going on and have somebody say 'look, it's ok.' You know sometimes that's all you need. Is for somebody to go, remind you of where you, you know that you actually are achieving something, that you are getting somewhere and that this is only a, a temporary thing you know. Yeah, I think a lot of people who are like that it would be really good if they had somebody at the clinic so when you went and got dosed you could talk to somebody. And that's the idea but they never have any time.' (#22, female)

'I do try to talk to my case worker at the methadone clinic, but she says she's not good in that [mental health].' (#28, female)

However, despite problems, larger treatment services did at least have the capacity to provide access to mental health support, often through in-house counsellors, a case management system, or by referring service users to other organisations:

'I've spoken to counsellors like um, the clinic that we go to up here, each of us are set a person that works in there. One of the workers will counsel us sort of thing, you know, case workers as they're called. Um, but I mean, ahh, I haven't seen mine since I've been back there, so, they just call you up and talk to you when they feel like it.' (#24, male)

'I went to them and said, "look I really want to start counselling here and um face-to-face counselling long term, so do you have anywhere you can send me?". So I sat with them and we got on the phone and started ringing up people and they've put me on to somebody.' (#16, female)

'…there's always someone to talk to if you want to. I mean a lot of people here they say, "oh no" and they don't want to help, they've got to help themselves before anyone can help them, y'know? I mean, and the counselling here, like at the clinic, I wouldn't say it's bad, I mean it's not top notch either but I mean they try and help you anyway they can. They do try and help you.' (#33, female)

'And the people here have always… like all those other people treated me like I was some sort of cretin with a disease, whereas the people here I have treated me like suppose more like someone who has mental health issues but still has a brain and um… They ask you a lot of questions about how you feel and whether that would suit your lifestyle and what's going on. Yeah, they take everything into account. And my case manager too. It's just a different approach.' (#65, female)

4.5.2   Accessing mental health services directly
In attempting to find help for their problems with anxiety or depression, some participants had approached mental health services directly, or had sought a referral to

mental health services from their drug treatment service, methadone prescriber or GP. Mental health services included psychiatric hospitals, community mental health teams, private psychiatrists, psychologists and non-governmental organisations that provide support for people with mental health issues. Because the majority of participants had experienced chronic, non-life-threatening presentations of anxiety and depression, most had not dealt with mental health services other than their drug treatment provider. The common, chronic nature of anxiety and depression tended to be the most obvious barrier to directly accessing mental health services; unless service users were judged to be a threat to themselves or to others, it was difficult for participants to gain access to public mental health services. Even when participants reported severe, acute distress or suicidality, they could still find it difficult to access mental health services:

> 'I went in there [the mental health service] one day right with blood dripping out from my wrist, ok, I had slashed, slashed my face with knives and everything, you know. I wanted to kill myself, I literally wanted to kill myself. And they went "oh, well go and find somebody to talk to and see how that works and you know just go home, take a few deep breaths, you know and then give us a call back tomorrow".' (#14, male)

> '…he's offered me counselling, you know, referred me on for counselling to the mental health team um, I contacted them, it took me three days to get an appointment, I got an appointment, I then spoke to someone for an hour who said, "oh, I'm not the right person for you to be talking to, come back in three days and talk to somebody else". Um, I went back the next time, they then took a few details and said, "oh no, no, this is just preliminary, you'll have to talk to someone else", so after a week, I just went like, y'know I can't do this, y'know I don't really wanna be here anyway, I'm thinking that this is gonna help me but just getting over those hurdles was too hard and they, y'know phone, I had spoken to them on a Thursday, I was having a really bad couple of days, Friday afternoon they rang me and said, "oh, if you feel suicidal, just call this number".' (#30, female)

For other participants, the combination of being identified as someone who had or continues to use illicit drugs and having a relatively common mental health condition, such as anxiety or depression, was a particularly potent barrier to mental health treatment.

> 'I can't remember the organisation, mental health but um because depression is such a common thing these days they wouldn't take me on because I had just depression but being that no-one's ever diagnosed me 'cause I wanted to go and see somebody, this was when I was into this self-suicide thing um... but yeah there wasn't, I couldn't find anyone to refer me on to anyone who would take me. It was... I wanted to be to able to see someone to fully diagnose me properly but they just thought, "oh no because you are a drug user and you've got depression that's not good enough" y'know, but who do you see if you want to get diagnosed properly if you can't go to them?' (#40, female)

> 'I was referred to the psychiatric ward there. I turned up there and, because of my drug use, they wouldn't touch me with a bar of soap. So probably after

that initial thing I walked out and just walked straight up to the dealer's and had a hit...' (#75, female)

The apparent prejudice of mental health services against people who use illicit drugs, or the lack of understanding of issues related to drug dependence, was overcome by some participants by lying or omitting details of their drug use. Other participants said that they had given up on external services and returned to their drug treatment service for mental health support:

> 'I went and saw [a mental health organisation], is it a national thing, friends and family of people with mental health issues or whatever. I went along there and one of the first questions was um, "are there any illicit drugs involved, 'cause if there are, you know, I can't help you". And so I went "no, there's not".' (#38, male)

> 'They [mental health team] are very anti-drug users, they don't really like us to use it, that's why I do most of my um, like my mental stuff through the treatment centre I use – you know. Because they're more um, they're not really worried about the drug side, they're more worried about the actual issues.' (#14, male)

Very few participants reported easy access to and positive experiences of mental health services. One man reported excellent integration of mental health and drug treatment services, with joint case management and intensive support, overcoming the barriers of having a 'low priority' condition such as depression and a positive history for illicit drug use. This positive situation seemed to relate to his diagnosis with schizophrenia as well as depression, and his case therefore receiving a higher priority for referral to a community mental health service.

4.5.3   Mental health support through general practitioners
Although not a common strategy, some participants deliberately sought help for their mental health problems through general practitioners, sometimes because of a trusted relationship with a known GP, and at other times because they could not get additional support from mental health or drug treatment services.

For those who had found a sympathetic GP and who had developed a trusting relationship with him or her, having a reliable source of support for mental health problems outside of drug treatment was highly appreciated:

> 'Um like I said that [my doctor] was quite a big help, I talked to him for an hour sort of thing, it wasn't just about what treatment I'm on or I should be on … we talked about general things. Like I said he is probably the only one who has been any significant help to me.' (#50, male)

> 'I'm very lucky in that I've got a GP who is really easy to talk to and who's very understanding about mental health issues. He has been fantastic; he actually has made a list of psychiatrists for me to contact but they all need to be paid and I can't afford that. So I'm just sort of making do with him.' (#72, female)

However, participants expressed a number of barriers to seeking mental health support from GPs, including: the risk of being identified in a general practice as a person who used illicit drugs, the lack of specialist training for co-occurring drug and mental health problems among GPs, waiting times, and the difficulty in finding a bulk-billing doctor.

> 'I've got two doctors that I go to um... yes... one of them prescribes methadone but I don't, I've never been to him they're just like family doctors, one's yeah... um... they both used to prescribe me my antidepressants and that um... one of them I don't see as much anymore 'cause he doesn't bulk-bill but the other one, he's really understanding...' (#40, female)

> '…a lot of people don't like going to see like a GP and don't feel comfortable talking with a GP.' (#26, male)

4.6   Treatment by medication

The service users recruited in this study could be regarded as a 'medicated group' in that nearly all (91%) had received substitution pharmacotherapies during their experience of drug treatment, and most had been prescribed psychoactive drugs like antidepressants or anxiolytics for their mental health problems. Treatment by medication was overwhelmingly the most common way that participants' mental health problems were dealt with by drug treatment, mental health and GP services. Because of their considerable experience in being prescribed and taking different medications, participants were asked to talk about their experiences of psychoactive medications including how they were prescribed, taking medication, opinions about their effectiveness, and decisions to start or stop treatment.

4.6.1   Antidepressant medication

For those participants who had been diagnosed with depression (95% of the sample), the majority had been prescribed antidepressants, with varying degrees of success. Many participants had been prescribed a number of different antidepressants over time:

> 'I've been on, yeah I've been on heaps man, I couldn't even remember most of them, but all the popular ones like Zoloft I've been on and Avanza and Efexor and all those sort of… last time I was on Cipramil like until around this time last year I think.' (#15, male)

While many participants described positive benefits of antidepressants (such as mood elevation and symptom control), many others (and sometimes the same people) talked about the apparent ineffectiveness of antidepressants or their side effects. Many participants described how they had stopped taking their antidepressant medication without consulting their doctor or had reduced their dosage by themselves. Sometimes this was in response to side effects, inefficacy, or because the participant did not want to be reliant on medication. Some participants had avoided taking antidepressants because they were not convinced they needed them, were worried about their effects, or did not want 'to take more pills'.

The main positive effect of taking antidepressants reported by participants was a reduction in severity of symptoms of depression, giving participants a greater ability to manage their lives:

> 'Yeah they've made a difference, I was able to cope for the first time without being overwhelmed with my feelings. Just get stuff done, get more structure in my life.' (#16, female)

> 'I went on a course for 12 months and it changed my life. It really changed my life.' (#22, female)

However, often the same participants could report side effects or problems in taking antidepressants. Reported side effects included tiredness, dizziness, nausea, disturbed sleep, and, in a minority of cases, fits or suicidality. For some the effect of antidepressants was to 'dull' their experience of everyday life:

> '…it was like blurry vision in the morning and you had a hangover and a furry tongue and do you know what I mean, that feeling that just a horrible, ahh, so I just stopped taking them altogether.' (#24, male)

> 'I'm not getting anywhere near as much, I know the Zoloft has partly to do with it and plus the methadone plays up with my sleep patterns and of a night time now I'll be going to bed at say 11 o'clock …and I will sit there until 4 o'clock in the morning and then I'll go back to sleep and I'll be up at 8 o'clock in the morning and then I'll go out all day, come home again and go through the same process and the by the end of the week I'm just absolutely rat shit.' (#17, male)

> 'I missed the high highs. Y'know, I miss my highs and the lows are part of life I'd come to accept. But the highs I missed, y'know, and that sort of plateau that antidepressants put me on I didn't enjoy really.' (#67, male)

Side effects were often cited as a reason that participants decided to stop taking antidepressant medication. For others, the apparent ineffectiveness of the medication they were prescribed was another reason to reconsider taking it, as well as a source of frustration:

> 'Antidepressants, Zoloft um all those other ones, you know what I mean and it's supposed to, they kick in after awhile, they kick in after a while, you know what I mean like, fuck I've been taking them for six months, when are they gonna kick in?' (#5, male)

> 'Okay so I was on antidepressants for a while and, and they reckon with antidepressants you know, you can't tell whether they're helping or not, people around you can, you know which was sort of this, kind of spurious way of saying "you might think they're not working, but they are really, believe me", y'know, and so I stopped taking them, and I mean I didn't really feel that different.' (#38, male)

Other participants stopped taking antidepressants for other reasons, such as not being able to afford prescriptions, and then found that they could manage without them:

> 'So I went to the doctor and he put me on the antidepressants and I was on them for about three months and then like, I, I think it happened, oh I didn't have enough money to get my script out and like the first few, I would say about the first week of not having the antidepressant, I was sort of up and down, but I can control myself now. I've learnt to do that myself, so I didn't need the drug to help me to do it.' (#33, female)

> 'I sort of stopped taking them, like I changed clinics for a little while and then with the transfer they didn't carry that across and I just forgot about it and um like it didn't make any difference to me like I didn't feel the change so I just kept on not taking them. Up until then I'd been on them for probably six months, you know.' (#15, male)

Some participants were ambivalent about taking additional medication, despite or perhaps because of being drug dependent:

> 'I use Cipramil more like a bandaid now. I'm prepared to go on it for a two to three months period and then stop. I've had doctors tell me in the past that they would like me to stay on it but I just don't like that idea. Yeah, so I use it as a bandaid.' (#60, male)

> '…some people can judge you and say "he's on antidepressants" or "he's on methadone, he's not clean" or y'know, it's about within myself whether I think I am clean or not or whether I am happy with being on medication or whether I am not happy being on medication... and I have never really been happy being on medication, it's been just like a last option...' (#47, male)

> 'I really don't want to enter into a chemical regime to try um to do anything about it [depression]. Um… I think a job would cure it.' (#4, male)

4.6.2   Anti-anxiety medication

Participants who had been diagnosed with anxiety were sometimes prescribed anxiolytic (anti-anxiety) medication, most notably benzodiazepines ('benzos') and other tranquillisers ('calmers'). However, many of the other service users had also been prescribed these drugs at some point in the past, sometimes as a result of depression, stress or difficulties in sleeping. Commonly prescribed anti-anxiety drugs included Xanax (alprazolam), Valium (diazepam), Normison (temazepam or 'normies') and Serepax (oxazepam or 'serries'). Some participants also reported that they were prescribed antidepressants as a combined treatment for anxiety and depression, or because their doctor was uncomfortable prescribing tranquillisers.

The risk of developing dependence on tranquillisers together with the fact that most participants had a history of drug dependence often meant that it was difficult for participants diagnosed with an anxiety disorder to access and receive appropriate medication. This meant that some participants felt they were denied effective treatment.

Other participants were fearful of or had become dependent on tranquillisers, and wished they had never been prescribed them. In a few cases, participants described how they had undertaken 'doctor-shopping' to obtain multiple prescriptions after becoming dependent on tranquillisers.

Some participants found that doctors (whether GPs, psychiatrists or drug treatment clinicians) were reticent to prescribe tranquillisers for anxiety-related problems, perhaps because of the well-known addictive potential of benzodiazepines and related drugs. If a participant was identified as having used illicit drugs then this also seemed to intensify doctors' reluctance to prescribe tranquillisers:

> '…he [my doctor] won't prescribe any, any tranquillisers or sleeping pills and if you're depressed or anxious you may not be able to sleep. And that makes life very difficult.' (#12, male)

> 'I went along and said "Look, you know, can I have some anti-anxiety medication like Valium or something?", and he goes, "Oh no, I don't think that's a good idea"... I think they don't like, 'cause people take Valium recreationally, I think they don't like prescribing it to people that have got drug history.' (#38, male)

When they were prescribed anti-anxiety medication (primarily tranquillisers), participants reported relief from anxiety symptoms:

> '…it's just something to take that edge off.' (#69, male)

> 'Valium relaxes you, if I can't sleep I take one and within half an hour I am asleep.' (#54, male)

> 'I just can't seem to turn off. The same with the goer, you know, there's that heart pounding here and after a while I want two Valium to stop my heart pounding, to get some sort of level because you can't sit alone and play with your old fellow and talk to the walls all night by yourself. Well, that's what it gets to.' (#69, male)

However, despite some benefits, participants also said that they had problems taking tranquillisers, or had reservations about their use. The ease with which some participants developed a dependence on tranquillisers was described as 'scary' and 'insidious', and lax or inconsistent prescribing practices were implicated in these problems. Trying to reduce one's use of tranquillisers was seen as very difficult by these participants:

> 'I've had a pill habit on sleepers and Valiums a couple of times and I, no it's, it's time that takes to stop, you know what I mean? It really, after um, having a pill habit of 50 or so a day, I, it probably took three months to even start feeling half like, I'd have, firstly the tears and just stupid ridiculous things, emotional wreck.' (#32, female)

> 'I've been to quite a few doctors with mental health, being treated for depression and trying to find the right medication, going on it and off it and

then they put me on bloody Xanax which is the worst drug in the world. But when the doctor gave [it to] me, I went to the chemist and said "Is this addictive?" and he told me it wasn't. Then he told me it was like a mild Valium... And um so yeah, I got addicted very fast and the town's only very small. There's a bigger town, further on where I used to be able to get the scripts filled. Then [the] pharmacy couldn't fill the script one weekend so I went without and I had a seizure within two days of going without. Yeah, so that was pretty scary. Yeah since then I've been trying to get off Xanax. It's a very addictive drug, very hard to get off.' (#64, female)

'At the moment I'm on, as well as methadone, antidepressants, Cipramil, and um trying daily to get off calmers – I didn't realise how insidious they were; I wish I'd never taken them. My doctor kind of pushed them on to me. "These are much better than Valium" when I'd only gone in there for one script of Valium.' (#66, female)

The need to deal with symptoms of anxiety, together with the recognition that the use of medication may be problematic, motivated some participants to try alternative treatments, such as counselling:

'…because I've had drug problems, the psychologist at Centrelink says that if I didn't really need to take the tablets, it would be better just to deal with the problem without using tablets, like counselling, which I'm doing now.' (#43, male)

4.7 Counselling, psychological or psychiatric input

Service users described diverse experiences with a broad range of mental health professionals including counsellors, therapists, mental health nurses, psychologists and psychiatrists. Caseworkers in drug treatment centres were sometimes perceived as counsellors or responsible for handling mental health issues by service users. Participants could end up seeing mental health professionals for a wide variety of reasons, not just for drug dependence or mental health problems. Reasons for seeing a mental health professional included:

- anger management
- crisis management
- domestic/sexual violence counselling
- family issues
- grief/trauma counselling
- job-seeking assistance
- relapse prevention
- relationship issues
- symptom identification/management.

While some participants took up the offer of counselling or therapy through a service they were already accessing, participants often reported approaching mental health professionals directly because of the difficulties in getting access to counselling within treatment services or through a referral system. Some participants reported seeing a counsellor as a compulsory part of treatment or parole.

Experiences of counselling were varied – most participants could talk about both good and bad experiences with mental health professionals, and could therefore outline what counted as good counselling or therapy for them. Positive experiences were linked to establishing trust with the therapist, perceiving the therapist as genuine, non-judgmental and having appropriate experience, and continuity of care. Symptom management and problem-solving techniques, such as those offered within cognitive behavioural therapy, were also valued:

> 'The psychiatrist in [the mental health facility] that I saw, he was just really good… He was just really, really brilliant and he asked really pertinent questions and um it wasn't that he said so much really, although he did have insights to offer, but they were always in the form of a question, "Do you think that may have been the case?", so that it was always me having to work it out. Yeah, that was really good. And the people here [at the drug treatment centre] have always… like all those other people treated me like I was some sort of cretin with a disease, whereas the people here have treated me more like someone who has mental health issues but still has a brain.' (#65, female)

> 'I mean, the one, the one person I've found valuable for counselling in this town was someone who used to work at the clinic and that was the only person in town that I, you know I went to her quite a lot because she was there and she made herself available you know like she did, outside of her work, we used to meet for coffee and stuff like that and have an hour talking with her um. It would have been great if they could do it through the clinic but they couldn't.' (#30, female)

> 'I've got a counsellor that I've had for a long time and she pretty well knows everything about, about that… probably throughout my using time which was like in the time I was using it was like I really didn't have any time off in the whole ten years. And um, she was probably the only woman that I was contacting like regularly, and that was only because she was a like a crisis lady and there always is a crisis, you know what I mean, so she was the person that I seen mostly for that whole period, so I became pretty honest with her.' (#15, male)

Negative experiences in talking-based therapies were linked to judgmental attitudes from counsellors, a lack of trust/rapport, a lack of continuity in therapy, difficulty in establishing regular access to a counsellor, and a perceived lack of experience on the part of the therapist:

> 'Well ah, it depends completely on which one you go to. I mean, they have counsellors and that at most, well at the bigger ones they do. Some of them

are more qualified than others and some of them are easier to get into than others. Um, they did a cognitive therapy thing at [the treatment centre] once um which was really good, but it's really restrictive with, like when you speak to the woman that ran that, she was restricted to a certain of number of days a week and a certain number, funding obviously.' (#11, male)

'I've seen too many textbook, as I call them, textbook counsellors… all the experiences they got is what they've read out of a textbook really…' (#24, male)

'…I've been to a lot of counsellors and stuff before but never really got anything out of it…. Um, yeah you just sort of feel like the same, they say the same things and you know in the end it's up to you to make the changes… I mean I think it can be useful to talk to people. But I don't know how effective it was. But when I saw the shrink, when I saw the psych, that was really good. He was, I don't know if it's just that I could relate to or what, 'cause that was a really big part of having counselling. If you don't relate to the person you're doing the counselling with, you're not gonna be open or honest with them. And most of the time when you're talking about it, from a drug user's point of view, you're never honest with anybody.' (#22, female)

'There was no trust with them. And I have huge trust issues – *huge*, through my background. And there was just never any trust and too much shunting me from one person to another. You'd just start to get to know someone and begin to feel that you might be able to open up to them and then they'd fob you over to someone else. It's just totally ridiculous for people like me. You've got to be able to know these people and trust them before you can open up and you know really come out with the issues that are important. And need fixing. So there's a lot of that.' (#70, male)

4.8   Self-management of mental health

Perhaps because of the rather varied and unpredictable access to formal mental health support when undergoing drug treatment, service users described a range of strategies or activities they employed to monitor, manage and improve their mental health status. These strategies were a mixture of informal and practical activities, and techniques inspired by counselling, therapy or self-help approaches. Self-medication with alcohol or other drugs as a way to manage mental health was also discussed by many participants, although many acknowledged the problems that can occur using this approach. Although self-medication could be problematic, the other strategies described by participants suggested that they were willing and able to try and improve their mental health, using the resources they had available.

4.8.1   Self-medication with alcohol or other drugs
It was common for participants to describe having used alcohol or illicit drugs to cope with anxiety or depression. Self-medicating was seen as a temporary escape from feeling

stressed, anxious or depressed and participants were aware that it was not a long-term solution for their problems. However, for some self-medication was seen as the only available way to deal with their problems:

> 'Yeah I deal with it [depression] my own way yeah, pretty much… Go and get a shot.' (#36, male)

> 'And I was using these drugs to medicate, self-medicate the feelings that I was having. Anything, if I was feeling anything that I could feel the energy coming up and I was sitting around… I knew I was gonna snap. So I would quickly run off, I had to try to keep it in as much as possible til I could get to something, smoke a bong or have a shot and medicate it.' (#16, female)

> 'I've always turned to drugs and stuff like that when I'm depressed 'cause it's all I know, it's pretty, it's very easy to get and, yeah. Too easy.' (#13, female)

> 'Makes me feel a lot better knowing that I can deal with it in other ways so I can, instead of going out and having a shot. I'd rather talk about it than have a shot to hide it.' (#17, male)

4.8.2   Practical/lay strategies to manage mental health

Participants described a wide range of informal and practical ways that they used to manage their mental health status. These strategies included:

- keeping active/busy
- talking to friends/partners/family
- going for a walk
- having a pet
- herbal remedies
- socialising
- listening to music
- focusing on your children/family
- exercise
- cooking/eating
- reading
- work/volunteering.

The aim of these strategies seemed to be to distract participants from depressing or stressful circumstances, and to do something pleasurable, energetic or rewarding:

> '…when I get depressed I sort of, I just go over to a mate's place, you know what I mean, and just don't tell him that I'm depressed but just go over there and just end up having a good time and just, gets it out of my mind and I forget about it.' (#21, male)

'I enjoy eating well, you know preparing my own food um… yeah shopping for it, etc. Um, I'm a voracious reader, you know I mean this is all in an attempt really to sort of um keep the black dog at bay or whatever, um, you know I do try and keep myself as active as I can.' (#4, male)

'I had a good way of coping with it [depression] basically I would go to the beach, sit on the beach, go bush walking um things like that' (#17, male)

'…when I first went off the antidepressants, I threw myself into the kids, you know like, doing their school work with them, going walking with them or whatever, just, everything revolved around my kids. You know, I made them the centre of my attention and that was it, you know, I just had to be a strong mum for my kids. You know they didn't deserve to cop anything that, I mean, I did myself. I mean, nobody deserves that because as I said, at the end of the day, it's my decision. Nobody's coming up to me going "give me your arm", ha, you know?' (#33, female)

'I'll end up getting pretty run down and depressed then and I'll just come into work and be like a zombie and fucking snap at people and you know and, luckily, just recently I've found someone else that's in a similar situation and I've been able to unload with them… and it's been really good to talk to that person, but before that, it was just something I had to deal with.' (#38, male)

'I have been on, joined the gym again recently, which is what I used to do when I got clean before and that also helps with the depression, it gets my blood flowing, it helps me with my self-esteem and that sort of getting fit.' (#47, male)

4.8.3   Counselling-derived and self-help techniques

Participants described a range of self-management techniques that were either directly derived from or had been inspired by counselling courses, participation in individual or group therapy, or from self-help books. Techniques included:

- positive thinking
- setting reminders
- self-monitoring
- anger management
- relaxation techniques
- visualisation
- meditation.

Participants described how finding simple but effective techniques they could apply in everyday situations had helped in managing symptoms related to anxiety and depression, as well as the broader stresses and strains in their lives:

'I think it was the combination of um family support and um drawing on the skills that I've developed through the process of um going through the

therapeutic community process and learning about myself and cognitive behavioural therapy type techniques, to try and change the negative thoughts and patterns I experienced.' (#71, male)

'It takes work though. And some people are really in victim-role and they don't know how to get out of that. And that has been so truly empowering to me, to realise that I don't have to be a victim, I can take control of my life and I can be happy if I put the work in. You know? It's been really a big release for me.' (#72, female)

'Yeah, if I feel like I'm having an anxiety attack or a panic attack, I do try and just breathe more calmly and just try to talk myself very calmly, just um as if… how you talk to somebody else. "It's ok… you know what this is, it's fine. It will be OK, you're just having a panic attack, it will pass. There's no real reason for it. You know you've had it before. It always goes away…", y'know, all those sort of stuff and trying to breathe – I guess it's almost meditational.' (#74, female)

4.9   Experiences of drug treatment

As a group with an extensive engagement in drug treatment, service users provided rich and detailed accounts of formal drug treatment, particularly substitution pharmacotherapies such as methadone. This section describes user accounts of drug treatment, detailing the ways in which users accessed services, the diverse effects of treatment and the quality of relationships between service users and providers.

4.9.1   Substitution pharmacotherapy

Service users discussed numerous aspects of drug treatment services that provided substitution treatments such as methadone or buprenorphine. The areas which drew most comment from participants were those related to: accessing the services; dosing schedules and procedures including takeaways; interactions with treatment centre staff and prescribers; access to other services; and effects of the drugs themselves – particularly methadone.

Experiences of various aspects of treatment services and modes of service delivery varied widely across geographical areas, and between different service providers and individual service users. There were however many general experiences that characterised service users' account of drug treatment services overall. Prominent themes emerging from within the accounts of service user experiences included: discrimination, punishment, management, and trust (or lack thereof).

In describing their past drug use and their decisions to undertake drug treatment, service users typically referred to unemployment, poverty and isolation from family, friends and mainstream social existence as motivators for engaging in treatment.

As described by service users, substitution pharmacotherapies tend to focus primarily, and sometimes exclusively, on drug delivery and dosing and tend not to deal with

physical or mental health or social support issues. Substitution treatment services most effectively attended to physical drug dependence and not other matters. Drug dependence appears to be experienced as the defining (and sometimes sole) identity of the service user in substitution treatment. Many participants noted that substitution treatment added another dependency to their lives, as substitution treatment does not free service users from drug dependency itself but rather replaces dependency on an illicit substance with dependency on a prescribed drug. Some noted that they were not given a choice between different pharmacotherapy treatments but were told which one would be most 'appropriate' for them. Participants also drew attention to the various ways that accessing substitution treatment worked to manage the service user and to control aspects of their lives.

Substitution drug treatment was described by many participants as a punitive regime. Service users described many mechanisms through which treatment services generated insecurity, anxiety, dishonesty and frustration. Interactions with service providers were often experienced as fraught and stressful situations and service users convey a feeling of constant peril; that of being thrown off a program on which they have become heavily dependent, or of 'lapsing' or 'relapsing' to illicit drug use.

Service users described interactions with service providers who are always busy and under pressure, situations where no-one within the treatment service has time for them and where they are constantly waiting. Some of the pharmacotherapy services described offered little in the way of understanding, too much in the way of negative judgement, and little appreciation of service user efforts and achievements within treatment. Service user accounts suggest that the priorities of pharmacotherapy services do not value service user needs in general, or take into account their mental and physical wellbeing.

While stability and the re-establishment of normal daily life are the goals underpinning treatment for most service users, substitution treatment services demand a routinisation of service users' schedules to comply with treatment. This institutionalisation within treatment can perpetuate social exclusion. The delivery of methadone or buprenorphine is not designed to support integration into normal working life, nor does it facilitate participation in family life (as evidenced by service user accounts over difficulties in maintaining child care responsibilities). Seen from a service user perspective, substitution treatment tends to maintain engagement in a culture of marginalisation and drug use, and with social groups and individuals that service users are often trying to keep away from.

Undertaking substitution pharmacotherapy treatment is associated with many risks for service users. Registration with a program can bring parents to the unwelcome attention of the department of community or family services and other welfare agencies and frequently brings the custody of children into question. Engaging with services does not necessarily afford users any effective protection from public identification and consequent stigmatisation as a drug user. Service users suggest that service providers, whether unintentionally or otherwise, often discriminate against treatment users.

Despite all these caveats, a great many of the service users interviewed described substitution drug treatments as a 'saviour', claiming that participation – while not always

successful in keeping them from using illicit drugs permanently – had helped them avoid crime, prison, destitution, madness or early death. Some service users also credited substitution drug therapy with enabling them to maintain normal family and working lives.

4.9.1.1   Accessing/starting programs

Most of the participants had been motivated to start a drug treatment program by some combination of the fear of becoming involved in criminal activity or going to gaol, the encouragement of partners, friends or family, or because they had run out of money.

> 'I couldn't find any more money without doing anything wrong.'
> (#35, female)

Others were enrolled in programs while in prison, as a condition of parole or as a result of hospitalisation or physical collapse. Most participants had hit 'rock bottom' in some area of their life and had run out of other options before considering substitution treatment – having emptied bank accounts, spent savings, ended up homeless or been hospitalised.

While referral through courts made participation mandatory for some service users, most had come to a personal decision to undergo treatment and gained referral through their GP or went directly to a known treatment centre.

Service users frequently found it difficult to get on to a program. Despite the fact that people reported feeling desperate when they sought help for the first time, a six-week waiting period was commonly reported. Due to long waiting times, bureaucracy, and difficulties in finding a supportive GP, accessing treatment for the first time often required perseverance and patience that was difficult to summon or sustain. This could be highly frustrating for service users:

> 'What am I meant to do? Go on using heroin? And then perhaps do crime so that I can afford to do heroin? When all these services are there and I can't get on the program…' (#67, male)

GPs were sometimes described as 'gatekeepers' to treatment programs. A few participants first accessed drug treatment on the advice of their GPs. However many other service users experienced being turned away by GPs, or felt their GP had delayed their access to a program or was letting their personal beliefs about treatment guide what they should do, e.g. endure an extended period of withdrawal before enrolling in treatment. Some participants described being afraid to complain about their GP's actions, in case their referral for drug treatment was affected.

4.9.1.2   Information about programs

Many services users knew about the availability of drug treatment and pharmacotherapy services through friends and other informal information networks. Often the location of a local treatment centre was known to them long before they used it. Some participants learnt about the availability of treatment programs through needle and syringe programs.

Those who approached service centres directly and found that they couldn't get on programs for six weeks had difficulty getting information on where to turn next.

> 'There's no sort of information. I think once I rang up [the treatment centre] for an appointment and they told me there's nothing they could do for six weeks. They um, I said, "So what do I do?", and they said, "Well, just ring around some GPs". I said, "What GPs?", and they said, "Well, y'know, just ring some doctors". And I said, "Well, can I get a [list of] prescribing doctors from you?" and they couldn't provide that.' (# 67, male)

First time potential service users said they needed to take a lot of the initiative to negotiate access to a system with which they were unfamiliar. The barriers could be daunting. Informal information networks played a central role when trying to find treatment services and supportive GPs to gain access to a program or clinic. In the absence of other information, informal networks were also relied upon by users to evaluate available treatments and providers.

> '…it's only through word of mouth that you could just find out which GP perhaps would [clicks fingers] just put you on that day.' (#67, male)

> '…everyone that I know sort of is involved in the drug scene, all my so-called friends or whatever, but um, they've always told me like if I could avoid [methadone] not to do it because it was harder to come off than the heroin and you know how it sort of gets in and saturates your bones and stuff. And I didn't want to, everyone said you know it's easier to lay down for three days than what it is to go on that shit.' (#35, female)

Aside from what they had heard through informal networks, service users knew little about substitution pharmacotherapies and treatment programs before they enrolled. They had little or no information about what to expect, and many felt misled (particularly over the length of time they were likely to need to remain on the program). In particular, little information about new drugs was made available to service users, giving rise to the suspicion among some that they were being used as 'guinea pigs'.

> '…when I went on naltrexone it, it was on the recommendation of some idiots that I bumped into on the street... They told me where to go and what to say kind of thing. I was one of the first people in Brisbane to go on the naltrexone, the first two days it was available. I sort of regret that because the way they sold it, it was like it was a miracle cure. And I think that… Also, this was a private doctor, he was the first person who was doing it, and when you bought the pills he just counted them out into an envelope. It wasn't until the third or fourth time I picked them up for a week or a fortnight's supply that there was enough so that I got the box that they came in. I got the sheet inside it that had all the side effects and everything and I just think it's a really dangerous drug. And I think there are a lot of side effects to it that I wasn't told about. And also we were guinea pigs in the sense that they didn't know over any length of time what it could do.' (#60, male)

4.9.1.3   Dosing: restrictions and inflexibility

Dosing schedules and the manner in which treatment is administered sat at the heart of the experience of substitution pharmacotherapy programs. Service users reported having to pick up their doses several times a week, if not daily. Dosing hours in treatment centres in particular were very limited and inflexible and took little or no account of social needs, emotional situations, or family or work commitments. Attendance for dosing at treatment centres afforded little anonymity, often little confidentiality and involved a lot of time waiting to see staff. For a few participants, attending a substitution program involved travelling long distances by public transport.

The accounts of service users suggest that those in treatment constitute a community of treatment users outside of mainstream, everyday life. This community could be a source of support (as in providing information about treatment services; see previous section) or a source of conflict. Service users often reported a history of antagonistic relationships with other service users with whom they would prefer not to cross paths:

> '…you've got nothing else to do so you talk amongst each other. And then somebody says something about somebody, y'know? And it gets taken way out of context, y'know what I mean like. If I got slapped at the bottom of the street, by the time I get to the next street, I've been shot three times. I've been stabbed once, I've been fucked, y'know what I mean, they're the Chinese whispers that get around.' (#5, male)

Problematic relationships with other treatment users were rarely accommodated by drug treatment centres, so some users preferred to arrange dosing at a local pharmacy (where available), in order that they could avoid other service users. Service users said the advantage of this arrangement was that they could just 'get on with it', 'get it out of the way' and didn't have to 'sit around gossiping'. Many interviewees also expressed a preference for private treatment clinics, or going to a GP who could prescribe methadone, largely because of privacy and convenience. However, these options were rarely available, and those that had access to such services counted themselves as lucky.

Service users described dosing schedules that seldom accommodated those who had to work early or overtime, or that made allowances for work related travel. One participant was told directly that the methadone program was probably not the right treatment for him if he wished to continue to work. Inconvenience and lack of privacy associated with dosing arrangements also made it hard for participants to keep their drug treatment private at work. Given the stigma attached to drug treatment this could be disastrous for a service user's employment prospects. Some service providers were more accommodating than others:

> 'I used to work for [a government department] um, in [the city] which you can imagine the client population, um and I went to a methadone clinic in, near [the city centre] and because of where I worked, they let me come out of normal dosing hours because I said look if one of my um clients sees me here, I'm doomed right. So they let me come out of dosing hours um and that worked well too, they were a lot better but the other one it was just like he

didn't care, as far as he was concerned, his hours were this and it's like, well, and he said "y'know, I'm open for three hours of a morning".' (#11, male)

The perceived inaction of staff and unnecessary inflexibility of schedules that cannot accommodate service users' efforts to normalise their lives (and make the most of opportunities) emerged as a source of enormous frustration and anger in the narratives of numerous service users. Often these frustrations involved missed job opportunities:

'Like for the last four or five years, we've been trying to go private or just get out of like, we've been telling them we want to get away from the drugs and all that, for our kids' sake and, the just like [my partner] was offered a job and then they wrecked that up on him like, they couldn't find dosing hours to fit him in which they could of, do you know what I mean? Like [my partner] even said like, "Give my takeaways to my boss", and like the boss waited nearly two months and then he just got jack of it and he said, "Look, I can't wait any longer, I can't hold this position open for any longer". That was $800 a week, we could have been out of that circle, but they done everything they could to block us from getting out of it, if y'know what I mean… and then because we went off our heads, then we had to have a case conference and we were in the wrong… [my partner] said to them, "Look, I have done eight years gaol, he was going to offer me a job", and their attitude is, "Oh one will pop up". Like, nothing like that will ever pop up again.' (#29, female)

Inflexible and inappropriate dosing hours also posed problems for service users with family commitments and young children in particular. On a daily basis many found that feeding their young children or getting them to school on time was difficult to fit in with the dosing times. Service users said that attending one-off events such as funerals or visiting sick relatives was often impossible.

Some participants also described strategies they had developed in response to the rigidity of dosing schedules and the consequent management and regulation of their own schedules. For instance:

'You could save a takeaway up here and there then, y'know, you've got a few to yourself. But, like I said, you've got three days and you've got to be back in order to get dosed. You can't get far in three days and do much.' (#25, male)

Services with more flexible dosing times permitted the development of strategies specifically aimed at dealing with the boredom or risk of waiting around for dosing. For some service users this involved getting the dose first thing in the morning so the rest of the day was clear, while others left it to the end of the day to avoid running into 'the desperates'.

4.9.1.4   Lack of anonymity
The public nature of presentation for dosing at treatment centres was an issue discussed by numerous participants. Long waiting times and the location or visibility of treatment centres or dosing clinics exacerbated these problems. In cities, participants who were employed felt particularly vulnerable to being identified while using the services.

Participants in smaller communities described anonymity as being pretty much impossible, even when they are using pharmacies for dosing:

'The person that you buy the takeaway tickets off is a friend of our mothers, y'know and things like that and yeah so it's such a small community and because you're dealing with auxiliary hospital staff as well, it's not just the clinic, because they send you somewhere else to buy the tickets so you go through the main hospital and everybody knows, they have voting at the hospital, when voting is on, they have fetes, things like that, that happen right outside the clinic, they don't tell you about it, that it's coming. And then you know, if you say something about it you know their response is, "oh nobody knows what this place is." [laughing] Who, who doesn't know? And if they don't know they'll ask the person that's next to them. [laughing] So yeah, that's been really hard that, trying to remain a bit anonymous.' (#30, female)

4.9.1.5   Attendance difficulties

Service users reported getting to the clinic during dosing hours or for other appointments could be difficult or stressful for a number of reasons including: lack of transport, work commitments, depression, anxiety, disturbed sleep, and child care or other competing responsibilities. These issues were often interrelated.

Transport posed problems for a variety of reasons. Service users often had no access to a vehicle or could not drive due to the loss of their driver's license, or could not get access to or afford public transport. Transport posed particular problems for service users in rural areas who did not have access to a local dispenser:

> 'I moved up to the country at one stage about a year and a half ago and found that I had to travel to a town in north western NSW, nearly 200kms away to get dosed three times a week and ahh, I did that for about month or so, about ten times. Hitching. Hitching with my child um it was pretty, oh well I got to know that town a bit better than I ever had before but um, y'know I'd find that I'd miss the bus back and have to stay overnight in a hotel.' (#18, female)

> 'There is actually a bus that comes up to the hospital but I think it, y'know yeah it gets in there at 10:10 and on the weekend, dosing finishes at 10:15.' (#20, male)

For some service users, their problems with anxiety or depression, or the combination of medications they were receiving, contributed to or exacerbated problems with sleeping. Experiencing erratic sleep patterns could make it difficult to get to attend early dosing hours.

> 'My pattern is um to stay awake all night. Whether because I can't sleep or don't want to but anyway whether it's easier to dose like um and also with my children this has been a problem too um a sort of sleep disorder which I think is part of the problem of depression I think um or it may be because of the bupe or it may be because of the [antidepressant medication] or a combination of both um. Where just to get there by 12:30 is kind of difficult and I'm often kind of ringing up and saying, "Look, it's 12:25 and I just woke up and you know, I'll try and get there in five minutes".' (#18, female)

The symptoms of depression were also reported as barriers to regular clinic or pharmacy attendance:

> '…when I get to the stage of being really depressed and I don't wanna see anybody, I really mean I don't wanna see anybody, I won't even answer my doorbell, you know or, the telephone or whatever you know, it's just, yeah me, myself and I… I can't go out.' (#14, male)

> 'Like some days I don't even like getting up out of bed but I know like if I don't get up, I'm gonna be crook by the afternoon.' (#17, male)

> '…even when I'm not depressed, it really, really bugs me that I have to go down there everyday and it's just like, I mean sometimes I can't y'know, I've got too much on to go down there. But yeah whether I'm depressed or not, it affects my treatment I suppose. Like maybe, you know, yeah I guess if I'm in the phase of staying in bed all day, that'll be a factor.' (#38, male)

4.9.1.6   Routine and stability

While depression can make it difficult to attend for dosing, one participant also pointed out that being required to make regular clinic visits could be useful:

'In some ways at some times especially when you are depressed, it's good to actually go out every day and sort of check in with someone y'know? So um yeah it was kind of like that sometimes, which is good, that they know you.' (#52, female)

In so far as dosing was seen as a constant and regular feature of service users' lives, it could also provide a sense of purpose on a daily basis. Substitution pharmacotherapies could also be seen as keeping service users in a more stable mental and physical state. However while providing an enforced sense of stability, dosing schedules severely limited the potential for service users to participate in activities external to treatment, and thus undermined the foundations on which a more enduring stability or normality could be built.

While substitution pharmacotherapies enabled service users to stop seeking money for illicit drugs, ironically substitution programs tended to emphasise the daily requirement to access a drug, albeit a prescribed and tightly controlled one. Access to dosing determined the possibilities for progress in others aspects of service users' lives. Ultimately the service user had to deal with dependence on a substitution drug. As one succinctly explained:

'…the only problem I have now is just to get off the methadone, because I'm not doing anything else.' (#33, female)

4.9.1.7   Takeaway doses

Service users participating in substitution treatment programs reported that access to takeaway doses ('takeaways') allowed them to participate more fully in regular activities such as work, family life, or going on holiday. Takeaways facilitated anonymity, and allowed some freedom of movement. For perhaps these reasons, takeaway doses were also seen as a currency to be saved for one's own use, or in rare cases exchanged or sold.

For those who described substitution treatment as a kind of imprisonment, or at least a serious restriction on their freedom, takeaways were seen as a kind of day release. However, service users described restricted access to takeaways, where takeaway doses were withheld by treatment staff and positioned as a privilege and not as a right of treatment. Service users often described a lack of transparency in how takeaways could be accessed, or how they were administered, and this was a source of frustration. When it occurred, withdrawal of takeaways was experienced by service users as a punishment and the threat of withdrawing takeaway privileges was seen as a mechanism of control exercised by treatment staff.

A strong theme in service user interviews was that of takeaway privileges being withdrawn unfairly – often because of something said in confidence to a counsellor, nurse or doctor. The possibility of the loss of takeaway privileges underwrote a commonly expressed desire to have as little interaction as possible with service providers. Service users did not want to come to the attention of their prescriber, were wary during consultations, and were not always honest about their mental or emotional condition, physical problems or any lapses in treatment adherence.

> 'I sort of believe in being honest: if you are upfront, people will sort of treat you well. But then I found out that there's no benefit to you being honest and that, 'cause they won't give you takeaways if you want to go away on holidays. Really I wasn't doing anything all that particular. I wasn't using everyday and but even [something] is enough to stuff up your records, so I just started lying and saying, "No I have been totally clean" um and that way, you can get takeaways when you need 'em, if you've got a job or whatever.' (#51, male)

While some participants seemed to get takeaways as a matter of course, others found access to takeaways was a lot more complicated. Arranging takeaway doses could require significant advance planning, and for some service users, "the run around" may involve being sent from place to place.

> '…where you buy [the tickets to pick up takeaways] is only open from nine to five. So you've got to get, and it's not open on the weekends and usually people get their takeaways on the weekends, so you have to make sure that you organise it in advance. Which is not something that drug users are very good at doing, organising things in advance [laughing].' (#22, female)

4.9.1.8   Relationships with staff/service providers

Trust, and often the lack of it, was the major index of the quality of service user relationships with service providers. A common complaint was that service users were stereotyped and were not seen as individuals warranting normal considerations by treatment staff. Many participants also described experiences of both unintentional and blatant discrimination.

'…all of my friends that use aren't street kids and, like, they're regular people and they've got families, but there's this whole picture that everyone assumes there's just other stuff that goes with [opiate use] and it doesn't necessarily.' (#48, female)

Participant evaluation of relationships with service providers was highly related to the perceived ability of staff to empathise, refrain from judgment, listen and provide support. It was also related to acknowledgment of service user needs and flexibility with regard to the treatment regulations (particularly dosing). Commonly experienced problems related to a perceived disinterest in or inability to help with mental health and emotional support issues, and the judgmental or punitive attitude of staff. Most service users had difficulty believing that treatment staff had any real idea of what they were going through while they participated in the program. The most common, and bitter, complaints about staff centred on their withholding help and support, most notably by withholding takeaways or not being flexible about clinic hours or times for appointments.

Participants tended to describe better relationships with staff at centres that provided a wide range of general support services, compared with those that only provided prescribing, dosing and drug counselling services. The quality of service user relationships with staff varied not only between but sometimes also within treatment centres, often being dependent on individual needs and expectations and the personalities involved. For some the comfort offered by a friendly listener was an important part of the support dispensed by the treatment program along with substitution pharmacotherapies:

> '…depending on who's on at the treatment centre, I can find it quite supportive sometimes. Like if my case worker's there um we always have a little chat or something. Sometimes it's y'know someone from an agency and someone that I don't like very much and y'know I might turn up kind of really wishing I could say talk to my case worker or something, um who I have a good rapport with um and she's not there and I end up kind of leaving feeling a bit shitty but y'know, I've had to go because of the [buprenorphine] anyway but, but there's often a lot of other support there that I really appreciate.' (#18, female)

Many other participants however, wanted to get in and out of the treatment service as quickly, and with as few interactions, as possible. The desire to limit interactions with service providers and staff to only the most perfunctory meetings was prompted by the perceived punitive nature of treatment, a distrust of staff motives and a consequent disincentive for honesty:

> '…your honesty with any of these services just puts you behind, y'know, to be honest you're just cutting your own throat it's like with, y'know the clinic, you tell them what they need to hear and what they want to hear rather than the truth because it's a, it's a punitive system y'know like people have their takeaways taken off them and stuff like that, y'know well that's not gonna help anything. So, yeah you learn how to, who you can talk to and what you need to say and what's gonna get you through but unfortunately I haven't found anyone that I could go, y'know feel like I'm anonymous and be honest, so it's hard to get any kind of treatment when you feel like you can't be honest.' (#30, female)

> 'I found them to be quite unhelpful. Like basically you're better off not telling them the truth; otherwise, if you tell them the truth because you want… I

don't know, some sympathy, a bit of an ear – that type of thing, what they want to do is… sorry, what they *do* do is immediately take your takeaways off you. You know? Like, "OK, I've just been assaulted." "Oh, we'd better [stop] your takeaways. They won't be safe." They did that to me, made me go in on Saturday and Sunday because this girl assaulted me and I said she knew where I lived. You know, I was upset I just wanted someone to talk to.' (#77, female)

'And most of the time when you're talking about it from a drug user's point of view, you're never honest with anybody. Because there's ramifications with being honest, yeah like, having your takeaways taken away or whatever so most people aren't honest and especially about, y'know how much they're using.' (#22, female)

Service users described feeling as though they were in a vulnerable position in their dealings with staff, and this led to a belief that it was safer to be unforthcoming and to keep unnecessary interactions with staff to a minimum. Treatment centre staff occupy positions of power as gatekeepers to the program. Many participants described the role of staff at treatment centres as more like those of prison wardens than healthcare professionals:

'…you walk in [the clinic] and go and see one person and they put you through this cell port thing like you're in a gaol and you either pay the money or they y'know, inspect you or whatever. And then you go through this other door in there and then somebody doses you and you get shoved out through a third door, I mean, y'know. You're treated like a prisoner basically it's ahh, a really horrific place.' (#4, male)

'…like they're prison officers who are nurses.' (#28, female)

'I'd say 90% of the staff they have up there have come from working in the prison system.' (#30, female)

In discussing their relationships with treatment staff, service users talked about the strategic need to remain docile. Many had witnessed events in which other service users had 'lost it', becoming agitated or angry in a treatment centre. Some participants mentioned altercations that they had had with service staff. While numerous participants acknowledged that wild, aggressive or erratic behaviour was difficult for staff to deal with, they also pointed to service providers' apparent inability to cope with user frustration, distress or anger, and reported poor responses to already volatile situations:

'…when people yell at them up there (at the clinic) they call the police. Y'know, I mean I just don't think that that's the best way of dealing with people, y'know, as your first option. To ring the police. And they should be in a position where they can um calm the people down, not make it worse, usually people have got [a] reason to be upset. They don't just come in screaming and abusing them for no reason. There's always a reason even if their behaviour's over the top to the reason, y'know? And they don't ever seem to deal with that. It's just, "Oh you're screaming so you should just piss

off. I won't talk to you". Y'know, people aren't prepared to let them, let, yeah I know, let them go you know to, I mean you can talk to people to calm them down and say, you know like, "I know that this is a problem, blah, blah, blah, da, da, da", instead of aggravating it all… [edit] they should all be trained in conflict resolution. Because usually it's something simple, and people can be calmed down, it's just that, they feel like, usually they feel like nobody's listening to them. Or nobody's taking it seriously.' (#22, female)

"I feel that when they know that I'm on a down or if they were a bit angry, they would press my buttons to make me more worse than what I am and then I end up going home in that state and make my family put up with my emotions [inaudible] and I did express myself to them in a nice way, but y'know, "It's no good what you's are doing to me when you see that I'm upset or something, don't press my buttons", I used that expression, "to make me worse," I said. "Because then you'd turn around and", as I said to them, "chastise me in a bad way or think that I'm bad and I'm not, it's just that, I've got five children at home and a little baby and you's don't know what I'm going through". They said they know 'cause they know that and they understand. They don't… I want them explain to us instead of just coming out and saying, "We've got to do this and do that".' (#28, female)

Numerous participants felt that staff claims to understand service users were patronising. Many service users described staff as lacking hands-on, real-life experience of working with drug users and those in treatment and 'only knowing what they read in books'. Some also asserted that clinic staff failed to see service users as individuals and stereotyped service users as 'junkies'. Others thought that, due to constant exposure to people in crisis, service providers had become hardened and unsympathetic to service user distress.

'Yeah, they're as understanding as they can be, but none of them have any, I don't think any of them have got any real sense of drug using other than it being a crisis, life-destroying thing for people, y'know, I think that's how they see it. And that's how they see you if you're in that, if you're part of that as well.' (#30, female)

Conversely, good experiences were associated with the presence of staff who were available and accessible and who were ready to listen, and who could understand and relate to users as individuals. Peer and ex-user involvement in treatment services was particularly endorsed for these reasons:

'…there should be more people there, or at least one or two people there that have been through what we've been through and, because they're only like reading from textbooks you know… they should have someone here that's like us, one of us that knows the go and I mean I think that would be good too if there was someone there that had come through the heroin and the methadone and come out the other end, y'know. Really good, I think that would help but I don't know if that's possible or not.' (#35, female)

On the few occasions where participated had encountered ex-drug users working in treatment services, the contribution of those workers was lauded.

While relationships of trust between service providers and service users were not the norm in the accounts we collected, such relationships were judged to be an extremely important aspect of treatment by those service users who had experience of them. Similarly, many participants described everyday problems with keeping up morale, sometimes due to mental health problems, the effects of treatment, social isolation, discrimination, exhaustion or lack of hope about the future. Thus interactions with staff who managed to convey their support in simple, humane and convincing ways, were highly valued by service users.

4.9.1.9 Pharmacies

Service users reported positive and negative experiences of pharmacies where they could attend for dosing. Some service users reported friendly and pleasant relationships with pharmacy staff, with participants saying they were prepared to travel long distances to pick up doses from a helpful pharmacist. A few expressed the view that their chemist was unsupportive or 'just in it for the cash'. Many service users experienced stigmatisation and discrimination at pharmacies, such as being made to wait while other customers were given priority. Others mentioned more overt discrimination and said they were 'treated like criminals'.

Compared with other service providers, far less was expected of pharmacists by service users (in terms of empathy and providing additional services). However, the ability to treat people as individuals and, if not to show active support, to refrain from humiliating service users, were issues that dominated many participants' accounts of their relationships with dispensing pharmacists:

> '…she works here a couple of days, she's a pharmacist, she is like pretty cool, she's a cool old lady, everyone gets on with her, she's really nice and she's got people's interest at heart. She will actually try to pull strings for you, bend over efforts – if it's reasonable. Whereas some of them, I mean some of the comments that you hear from some of the staff, you know they just shouldn't be there. One guy had been trying to jump off [methadone] and he had been really fidgeting, he'd gone back on and the woman behind the counter went, "Oh you I knew you'd be back", and it's a real [both laugh] it just about broke the poor guy.' (#46, male)

Many service users commonly talked about not being served in turn and regularly being made to wait until all other customers had been served:

> 'I just don't think the chemists understand enough about what they're doing, really, I don't think, most, for the most part they're not malicious or, or even sort of knowingly prejudicial but they just don't understand and they think, even though they know that I have to go to work and I've got a job and stuff, they sort of think that I don't and I've got plenty of time to just stand around there and wait for them to, you know serve me and it's almost like, they sort of see every methadone patient, not as individuals but just as a group that, all act the same, look the same, so, it's kind of weird.' (#38, male)

It was noted by service users from smaller communities in particular that being seen waiting at the pharmacy every day (for dosing) increased the chance of identification as

a drug treatment service user. The resultant stigma could affect not only the service user but also their family and children.

4.9.1.10 Prescribing doctors

It was common for service users to characterise the prescribing doctors overseeing substitution treatment as doing little more than writing prescriptions for methadone or other drugs. Prescribing doctors within programs were not considered available for other health care advice or to deal with health issues other than those directly related to the effects of treatment. Drug treatment service users therefore reported seeking help or advice from other health professionals on health matters not directly related to drug treatment or dosing:

> 'I just don't get sick, but if I did have something else wrong with me then I probably would go to another doctor, more so because he [my prescriber] is very busy and to get it would require a couple of weeks on the waiting list but even if it was another physical ailment or if I did have mental health stuff come up I'd probably be inclined to pick a doctor with, that I felt had more experience in that, I really see him as the prescribing doctor which is kind of sad. That makes it sound really bad, he's a nice guy and very professional in what he does on the prescribing side of things... I suppose... if I had that sort of stuff going on then I would relegate him to being "the writing hand".' (#45, male)

> 'She just said, "Oh, right. You should see someone about that", [low blood pressure blacking out and fits] and I said, "I thought I was! I'm talking to you". But no, she preferred I went to my GP.' (#67, male)

Some service users acknowledged that treatment programs were often overloaded, and that prescribing doctors did not have time for consultations about other health issues. Service users thought that many prescribing doctors situated themselves as purely 'methadone prescribers'. Others thought that through working as substitution prescribers, doctors sometimes became less competent in dealing with other health issues.

> 'I think that everyone can appreciate that he is giving up a lot of time and potential income because he is a really good doctor and I am sure that if he was seen in another capacity then he would be charming and have a lovely bedside manner and the rest of it but when it comes down to the methadone thing and the waiting room is full, you do feel the obligation to move through and it does become like this treadmill of, "In, next, how's it going, what dose you on, what dose you want? Thanks, next", and I think if someone said they've got depression then he would try to help but I think it would also be a case of, "that's not what I do, try smiling more?".' (#45, male)

Service users frequently described having to act a part, or 'play the game', and experienced consultations with prescribers as a kind of test – a time when they felt that questions were loaded, and the consequences of 'slipping up' and giving away the 'wrong' information could be disastrous for them. A frequently expressed opinion was that the more attention the service user received from his or her prescribing doctor,

the more likely it was that they would experience a negative outcome in terms of their treatment arrangements.

When discussing dosing, most service users reported little or no discussion with their prescribers about dosage level after a stable dose was settled on early in the user's treatment program. The standard consultation as described by participants consisted of a single question:

'"Are you right, do you need to go up?" – that's it.' (#10, female)

However some participants described excellent relationships with their prescribing doctor, characterising them as understanding, supportive and accommodating. These service users tended to identify this relationship as central to their wellbeing and an important aspect of treatment. Prescribing doctors who were highly regarded were seen as respecting and recognising service users as individuals, employing a holistic approach to patient care and enabling and supporting the service users' normal life activities. Valued doctors often had established prior relationships with service users when acting as a family doctor or GP.

'…when I was married and I was on it [methadone] for that two and a half years I had a very good family doctor who would just write me scripts for [it] in tablet form so that we could have holidays abroad as a family but... because if you try to get tablets to go away anywhere, it's like you're asking for the moon... how are you meant to, live a normal, y'know that's the whole idea of it is so that you are supposed to try to get back into your normal things… I mean it's only that that family doctor was really, he was great and he was quite prepared to take the slap on the wrist or whatever if you got it for doing it... um but he felt it was more important keeping the family unit together and me doing normal things than going without my dose for two or three weeks and being tempted to go looking for other substances when I am in foreign countries, y'know I mean it makes sense doesn't it?' (#42, female)

4.9.1.11 Access to other services

The number and type of other services that service users reported having access to through drug treatment programs varied between treatment centres. Large treatment centres in urban areas tended to provide the widest range of services, including education, peer support and social programs. Most participants who received substitution treatment through public clinics or treatment centres had counselling and case worker support available to them, but in many cases these services were not widely trusted and could be perceived as policing rather than supporting service users.

Many participants found that their program offered little assistance with mental or physical health issues or social and legal support, and did not always have information available about where users might turn to get these kinds of support. Some participants described instances when treatment centres and services provided assistance in accessing external services, but only if the user made a specific request.

Drug treatment service users tended to be dependent on the support provided through treatment centres for all their needs as few other services would deal with them. The

need for other services was accentuated when service users were trying to manage the additional burdens of depression, anxiety or complex vulnerabilities.

Services users described accessing in-house mental, physical or other support services at clinics and treatment centres as generally involving delays and waiting for staff availability. Some service users spent much of each day at the clinic:

> 'If you go in for a dose, you're out fairly quickly but if you come to see a doctor, you just sit around for hours.' (#12, male)

> 'I might as well just stay here; it's my home from home [laughs] instead of coming back.' (#62, male)

Many participants had at some time needed to access accommodation services, for crisis or long-term accommodation. Access to accommodation services varied across treatment centres and was reported as generally more difficult for men to obtain. Other information and support services that participants identified as difficult to access included legal services (including advocacy), particularly for those who were worried about losing the custody of their children.

4.9.1.12   Effectiveness of treatment

When talking about their treatment goals, service user participants described wanting 'normal lives', with stability in housing, employment and relationships. Service users were also looking for information and education on how to better manage everyday life.

Substitution drug treatment can, and often did, help service users find a degree of stability and security in their lives, not least by diminishing the need to turn to crime to fund the purchase of illicit drugs:

> 'I know that the methadone is always there, I have always got a dose waiting for me every morning and that, that I'll, it will all, it will make everything OK.' (#57, female).

> 'It makes me feel [like a] normal person. There's no highs, there's no lows, there's no wanting to use, there's no … you're just a normal person. The only thing I do different to everyone else is that I need to go to a chemist every day.' (#59, male).

It should be noted that stabilisation means different things to different people. In general participants were referring to stabilising their daily lives. Different levels of drug use were considered indicative of stability by service users. While some saw abstinence as a sign of stability, others sought to maintain occasional or regular use of pharmacotherapies or illicit drugs. Service user and provider goals were therefore not always in alignment.

Participation in treatment could also continue or intensify a sense of marginalisation and isolation among service users. Some thought that depression might be a side effect of pharmacotherapy drugs or was exacerbated by the experience of treatment. Many

reported stigmatisation and discrimination within treatment services and beyond, and their employment, study or normal family life tended to be impeded by participation in treatment. For these reasons, service users often acknowledged the benefits of methadone and other pharmacotherapies while also remaining cynical about their prospects:

> '…see, most addicts start using because there's underlying issues that you just don't want to deal with, OK? "I can't deal with... whatever." The methadone keeps you, keeps it, suppressed basically. It's the truth. Without having to do the crime and come up with the 50 dollars every time you need a shot – or 100 dollars, I'm going back some rah rah rah. So it helps that way, just to keep you sane enough to be able to function on a daily basis without having to run around robbing everyone. Yeah, that's about the truth of it. Apart from that it doesn't help. I think really it should go hand in hand with counselling. It doesn't, of course, but… I mean, they've got counsellors there but they don't counsel you at all. It's, like, crap. They do everything they can to destroy your life if you ask me [laughs].' (#70, male)

The effectiveness of methadone for overcoming heroin dependence was not the same for everyone. Many participants reported being engaged in the methadone program for more than a decade, and others had come to realise that their treatment would continue for many more years. Participants often described numerous 'relapses' to problematic heroin or other drug use and a few continued to use heroin as well as methadone. Some service users said that methadone simply didn't work for them:

> '…if it was effective treatment I'd tolerate [it] but it's just not an effective treatment, and the idea of eventually having to withdraw from methadone is just too daunting. I never want to do it again, at all. It's really awful.' (#12, male)

One participant, who said he had successfully stayed off heroin due to methadone treatment, suggested his success was due to having reached an appropriate stage in his life where he was ready for change:

> '…[methadone's] working out at the moment, like I said, for the first time. Mainly it's working out, and it's been um probably nearly ten months, like almost a year I've been off heroin… and in that time, I think mostly because of methadone, I've been able to keep the same address for that time and like even have little bits of work here and there and stuff but um, like I don't think it would have happened without being on methadone… I think it's the stage I'm at in my life, like I've been on methadone and that before and it hasn't changed anything, you know what I mean it's just like, I guess the way I'm using it has.' (#15, male)

4.9.1.13 Effects of methadone

Methadone was the most commonly experienced substitution pharmacotherapy by service users, although (as indicated previously) it was not necessarily popular. Participants often thought methadone could be bad for both mental and physical health, but that without it their lives would be worse.

Service users described beginning methadone treatment as particularly difficult. Not being intoxicated by illicit drugs freed up time to think about other aspects of their lives, and this could be challenging.

> '[Depression occurs] mainly when you first start on it and you don't know what to expect. Um, a lot people will say, "Oh, you may get, you may get off your face on the methadone." But I found with the methadone I wasn't getting stoned on it, it was keeping my thoughts away from the heroin and more on what I want to do with my life and you know, how I wanted to face my kids without having that problem behind me, y'know so I mean, in the long run it will be behind me, but you know, not standing right behind me going, "look, I'm still here, don't forget it".' (#33, female)

In some cases methadone was associated with symptoms similar to those related to anxiety and depression, making it difficult for service users to distinguish mental health issues from the side effects of treatment:

> 'And methadone? I just felt really sluggish on it all the time, severe constipation and when I changed over to [buprenorphine] I seemed to have a bit more energy – not as much because I still have days where you don't do things… I actually get up and do a bit more. I had to force myself to do that at first because I've been used to not doing anything for so long. You sort of have to force yourself to get up and have a shower and do some work – or anything, y'know? Just getting up and doing something.' (#76, female)

Some participants described methadone as making them feel 'flat', 'dull' and 'numb', while others experienced debilitating side effects:

> '…it just numbs you, it dulls your motivation, you don't get stoned, you get zombied.' (#2, male)

> 'I tried that [methadone] and my legs throbbed and I got the flu and I got so damn depressed I couldn't cope. It wasn't working and I felt trapped and that and I just jumped off it. I didn't want to live anymore, so I didn't want to kill myself so I jumped off it. I practically went into convulsions almost.' (#41, female)

Withdrawal from methadone was seen as particularly difficult, compared with withdrawal from heroin. This was often a source of fear and trepidation for service users seeking to reduce or stop their methadone intake.

> '…it's [withdrawal from methadone] not like heroin, it takes a lot longer and it's a lot harder and it's a lot, oh it hurts a lot more. Y'know, I've come off heroin a few times y'know and in a week, you're ok. Y'know, you can sort of stretch in the sunshine, you can honestly feel. "I feel good today and it's only been a week". Y'know, I've done that before but – methadone was different. Yeah, I got hooked on Viceptone which is methadone and it's, I've never been able to get off.' (#20, male)

'…it takes about two or three days before you start feeling sick and then you get really sick, it is unbelievable, compared to heroin it's like 10-times worse, 20, a 100-times worse, it's unbearable.' (#12, male)

Service users' feelings of dependency of methadone, together with the way treatment (and dosing in particular) is administered, meant that users often saw methadone programs as a form of incarceration or policing, with methadone seen as the 'liquid handcuffs' tying people to treatment:

'…it's very much, "I'm going to replace an illegal drug with just another drug that is more restrictive because I can only get it at certain times." I have to answer to these people.' (#74, female)

'I just hate the handcuff access, y'know? Every day you've got to go. And you get treated like a junkie; they treat you like… You've all got to stand on a certain line and you get served last and it's just ridiculous.' (#54, male)

'…the problem with methadone is that you're chained to it, you know you can't go away without a lot of drama organising takeaways or getting doses somewhere else.' (#22, female)

'I definitely call it [methadone] "liquid handcuffs" because I am chained to something on a daily basis.' (#69, male)

'…it was gaol y'know, it was like gaol. I mean like going, if I turned in a dirty urine I'd get bounced to gaol.' (#2, male)

The apparent benefits of methadone were therefore often weighed against many perceived limitations. This meant that many service users were ambivalent about recommending methadone as a form of drug treatment, but given a paucity of appropriate alternatives, felt no option but to continue:

'I don't want to sound like I actually advocate um methadone as an alternative but I'm afraid to say given the um given the circumstances, well then it is the only alternative for me at this time.' (#8, male)

4.9.1.14 Effects of other pharmacotherapy drugs

Service users discussed other pharmacotherapy drugs far less frequently than methadone, although a significant minority of participants had tried or were receiving newer treatments such as buprenorphine. Compared with methadone (as it often was), buprenorphine was described as facilitating 'more normal' levels of daily activity, leaving the user more clear-headed and able to make decisions. On the negative side, for some it was associated with sleep problems and a loss of sex drive. Many service users (even those who had not been prescribed it) believed that buprenorphine could be used as a useful aid in withdrawing from methadone.

The few participants that had experienced naltrexone associated it with unpleasant side effects:

'Makes you feel really bizarre, it's horrible. Have you heard this before? But they give you all this other these other drugs, prescription drugs to counteract the bad effects of the naltrexone, and I don't see the point do you know, you're substituting something illegal with way more legal stuff. So I didn't want to take all this huge array of prescription drugs and the naltrexone by itself makes you feel like crap, anxious, you know, your heart's racing, sweating. It was horrible. But do you know I am saying I had this huge cocktail of other drugs, so yeah I didn't stay on it very long because I couldn't handle taking it just by itself and I'm sure anyone else that did the same as me would tell you the same it just makes you feel terrible.' (#48, female)

Side effects in general were often a strong marker of whether substitution pharmacotherapies were seen as usable, effective or acceptable. Service users were particularly concerned if they thought that their medication was affecting their psychological wellbeing by making them feel depressed, anxious or aggressive. Ultimately, other treatment drugs were decried or lauded based on the degree to which they enabled or hindered service users to return to 'normal life'. This emerged as a major measure of evaluation:

'See the beauty of the methadone is, well it's a good stop gap in that it provides you with an opportunity to rejoin the community. I don't say it's the answer, in fact I don't say it's the answer at all. I think it's a very poor alternative to giving an addict substances he's addicted to, in my case heroin. But it has provided me with the opportunity to at least maintain some sort of semblance to normal life.' (#8, male)

4.9.2   Other drug treatment

In comparison with the extensive discussion about substitution pharmacotherapy programs, service user participants said relatively little about other drug treatments such as residential rehabilitation, detoxification, group therapy, and participating in 12-step and total abstinence approaches.

Like participants in substitution programs, service users who had engaged with other treatments particularly valued non-judgmental treatment situations. While participants were largely positive about the staff in other treatment services, the negative impact of judgmental attitudes on service users' experiences of treatment was an issue raised by a number of participants.

Group counselling was a part of drug treatment about which participants most frequently expressed an opinion, and peer involvement in programs received the most positive comments.

4.9.2.1   Accessing/starting program

One of the issues reported by service users was a lack of preparedness about what to expect from treatment programs – particularly what was regarded as 'success' in treatment or how long treatment was likely to last. This could reflect the fact that service users rarely mentioned deliberately accessing treatment programs. Instead participants

described being 'handed over' or 'landing' at treatment services. In some cases treatment was ordered by a medical or legal authority.

> '…initially I had really no idea what kind of services where available until you know it was the crash and burn and ah I found myself in the detox unit.' (#39, male)

> 'See, at the beginning I really didn't know anything about getting over heroin. I thought they were just going to just fix me. I thought I'd got there [a residential rehabilitation unit] and they'd fix you. That was a bit of a shock… because I really didn't even know it was going to be a lifelong battle. I just thought, "Oh, I'm prepared to stay here for a long time as long as they can fix me", but I mean I left after eight months to sneak up to Brisbane and stuff – using.' (#60, male)

Participants' accounts indicate that while their initial gesture may have been one of submission or giving themselves up to treatment, they then found that active participation was often demanded of them (particularly in residential units). Participant assessments of their treatment experience as positive or negative, useful or destructive, were largely a function of how ready they felt for this participation, and whether they experienced it as choice or coercion.

4.9.2.2 Group sessions

Many participants had not tried group therapy, and while not opposed in principle were often not attracted to the idea. The need to talk in front of other people (particularly about illicit drug use) was a commonly cited barrier to participating in group work:

> 'I'm not one to really talk about things. I talk to my doctor or one person who I've been talking to and have a rapport with. I'm not one to… I haven't in the past been involved in groups like that. I do see their benefits and I think it's something that I would have to get my mind to accept and like, get with the program, to be part of, and I haven't ever taken that step.' (#76, female)

Other participants were more explicit about what underpinned their reticence to talk about their experiences in group sessions. They cited a variety of reasons ranging from self consciousness, anxiety, to cynicism or a lack of belief in group processes. Most often service users said they found it hard to listen to self-indulgent or self-pitying accounts from other participants and thought that group discussion tended to become unhelpfully fixated on illicit drug use. These criticisms were associated with the view that spending time with drug users or those in treatment could increase the desire to use illicit drugs:

> 'I've found in the past that when you go to these things, all it does is make you want to use more. You start talking about it and it just gets all, y'know… I don't know whether actually talking about all your worst drug experiences and all that stuff is beneficial.' (#22, female)

> 'Most of them sitting there talking about, "Oh, back in the good old days when I was getting [inaudible]", it just made me want to leave the program, leave that night and get on it, and so I did.' (#25, male)

While participants' attitudes to group counselling tended to be negative, some had found the experience therapeutic. A few found that it was an important first step in addressing problems underlying their drug dependency and that group participation lessened their sense of isolation:

'It was the [local] drug and alcohol council and that was the first time I'd ever met another gay man and that changed my idea about what my potential future could be and that I didn't have to face the prospect – which I had always thought – which was like growing old on my own and with no companionship or support or whatever. And also being ostracised from the family. And so through that process of meeting that other gay man and talking to him and actually coming out to him (this was the first person I'd ever come out to) and all that, y'know, doing intensive peer group therapy and then one-on-one counselling on a regular basis (like three times a week) and also I disclosed the sexual assault stuff and had specific sexual assault counselling outside of the rehab.' (#71, male)

Once again, choice was an important determinant of the perceived value of group counselling for service users. Little value was generally placed on group participation by those who had had participation imposed on or required of them (such as by a court).

4.9.2.3 Relationships with staff and peer workers
Service users were largely positive about their relationships with staff in services providing programs other than substitution treatment. However some participants felt that they had not been given a fair opportunity to benefit from detoxification and group counselling precisely because their participation was compulsory. These participants perceived that staff had pre-judged them, labelling them trouble makers and excluding them from group activities. These service users consequently felt that any efforts they had made were not valued, and that their chances of succeeding in treatment had been undermined.

Perceptions that staff were trying to force rather than encourage participation were strongly resented:

> '…when I was in [the rehab] I didn't like the counsellors, they used to go off at me for – what was it – not participate, not participating in something dialogue or whatever cause I wouldn't talk about my experience – I dunno – yeah it was just depressing to hear about everyone's life and that, I mean we have all gone through it... there was no solutions it was just problems.' (#40, female)

In contrast, participants were consistently positive about services and projects that involved people who have used illicit drugs or peer workers. The involvement, or absence, of peers appeared to be the major marker of difference in the participants' assessments of the quality of services:

> '…the nurses and that that are there, the staff especially are all ex-addicts y'know so they really understand what us addicts are actually going through, y'now and that's what makes it such a good service.' (#14, male)

'And the guy who was running [the program], I came religiously every Monday of every week because he just inspired me. He was an ex-user himself, newish, a bit trusting.' (#77, female)

The reassurance and understanding that can be offered by staff who have been in similar situations, and have experienced the same kinds of problems associated with illicit drug use, was seen by service users as combating their sense of stigma and isolation. Furthermore, peer involvement was seen as providing valuable and achievable models of how to participate in and contribute to treatment. Nearly all of the interviewees had been on numerous programs and many said that they did not feel that they would permanently overcome a sense of addiction or drug dependence. Service users appeared very wary of setting themselves up to fail. Peer workers could therefore be seen as sources of inspiration or living examples of what could be achieved in treatment, despite its difficulties.

Those participants who had been involved in volunteer or peer work themselves were also highly positive about the programs' direct and practical impact with regard to harm reduction in the community, and also about the positive effect participating in programs as a peer had on their own wellbeing:

'I love this place [local drug user organisation]. It's changed my life getting involved with [this organisation]. Over the last three years I have gone full circle. It's really helped me I think because it is peers, because you're not working for somebody, you're working with them, and I do volunteer work here as well – that really helps me, giving something back and participating in something and being part of something that's bigger than me. I feel part of a team now and that is so good for my self-esteem. It's been wonderful. Yeah, lots of support.' (#72, female)

'I think one of the things that has really made a big difference in my life um, as far as mental health goes and as well as my illicit drug use goes, is having worked here at [the drug user organisation] where I'm not judged and where I can just be who I am and not have to hide anything and, and that has really, like I used to be a lawyer and I kind of um, I worked a law firm and I really felt that I couldn't be who I am y'know… I couldn't tell anybody anything about my personal life and, it was just very awkward and I felt that I didn't belong there. Whereas since working in the community based area I've felt a lot more comfortable, especially at [the drug user organisation] where there are other people like me who are not going to judge me and yeah that's been such a positive factor in my life as a whole. It's really got me back on to the – I don't know – the straight and narrow path and stuff, the right words, it's not, it's got me to the point where I can be functional and relate to others, others who are in the same situation as me, y'know? To have peer support I think is, is one kind of treatment, if you can call it a treatment, um one kind of activity I suppose, which is really underestimated for illicit drug users. I think um there definitely needs to be more peer support.' (#52, female)

Both support for and the active participation of service users were seen as integral parts of successful, non-medication-based rehabilitation. Participants involved in peer work

described it as not only worthwhile (in helping others to help themselves) but also as stimulating and positive in their own management of drug or mental health issues. One participants described how her involvement in peer work had encouraged her to initiate and generate new projects:

> 'I answered an ad in the paper looking for people to be peer educated and, after what I'd been through... And I did know of [my local drug user organisation]. I used to get things from [the organisation] but that was all I knew about [them]. So it looked really interesting and so I answered that. Then, when the project wound up, there was no-one doing it. People kept asking me what happened, where has it gone, why isn't anyone doing it? So I just started doing it voluntarily. I just started up a project by myself and eventually got some funding for it.' (#74, female)

4.9.2.4 Effectiveness of treatment

Most participants talked about treatment goals in terms of management of their drug dependency and participating in or rejoining normal life activities. The concept of 'total abstinence' was not one that many participants felt was achievable or desirable. However some service users were strongly in favour of total abstinence, often after successfully participating in a 12-step, Narcotics Anonymous-style program, and had shifted their treatment goals accordingly:

> 'I am not keen on going on a long-term maintenance of a, ever since I have been introduced to what total abstinence is about, every time I have gone onto a substitute drug treatment I have never felt comfortable with it.' (#47, male)

However in most cases, participants said total abstinence was an ideal that they could not live up to. Few service users had found abstinence sustainable, and few had got past the first few steps of a 12-step program. Many said that the sense of failure they experienced if they 'lapsed' and used drugs while taking part in a 12-step program was too demoralising. Some participants describe a resultant sense of worthlessness and despondency that kept them away from meetings or led them to find solace in increased illicit drug use.

Some participants pointed out that while in the past they had found Narcotics Anonymous methods and total abstinence approaches inappropriate, they had returned to those methods and goals at a later stage of life. Similarly several of those who currently found the confessional aspect of group therapy to be deeply problematic, also said that perhaps at some point they would come to feel differently about the need for it. Some participants suggested that the suitability and effectiveness of group sessions was dependent on the stage of recovery and state of mind of the service user.

Necessary steps in recovery identified by participants were those of coming to accept the ongoing nature of the recovery process and changing or leaving behind the past. Numerous participants pointed out in various ways that the latter was supported by an outward and forward-looking approach rather than a focus on the self:

> 'I don't want to become the arsehole that I was, forever desperate and "poor me", self-centred. I'd rather help somebody.' (#69, male)

Those service users who had experienced peer involvement and peer work were extremely positive about its effects on other service users, the wider drug using community and peer workers themselves. Peers employed in treatment services or in voluntary programs noted the value of being able to contribute in an inclusive and non-judgmental environment. One participant specifically identified undertaking peer work as a form of treatment in itself.

Peer involvement in treatment and other programs addressed most closely the predominant service user framing of treatment goals and principles: fostering a participatory and outward-looking approach to goals and achievement, offering supportive and understanding environments, and modelling positive strategies and attainable goals. Last, but not least, the aid given through peer worker harm reduction activities in the community was seen as a way for service users to 'give something back' to the communities they live in.

4.10   Relationships with general practitioners

GPs who treated service users as individuals and who took the time to talk with service users with respect were valued most highly by participants. Those participants who had relationships with GPs that were characterised by trust and respect cited these relationships as major factors in both their overall wellbeing and positive treatment prospects. A few participants reported relying on their GPs for counselling and other mental health support.

While GPs were highly regarded by some participants, others expressed low opinions of doctors in general, making claims such as:

> 'I'd be having my leg cut off or coughing up a lung or something before I turn up to a doctor.' (#51, male)

4.10.1   Accessing health care in general practice

Many service users did not have an ongoing relationship with a GP, and faced problems finding a suitable doctor to address their general health issues. Trying to find a suitable GP was prompted after participants moved house, lost confidence in, fell out with or were turned away from an existing doctor, or in some cases an existing GP died or ceased practicing.

Service users reported having to deal with the negative attitudes of prospective GPs, and some found they were refused appointments when they disclosed problems with drug use or ongoing treatment for drug dependence. Many service users had approached a number of local GPs, trying to find one who was able deal with their issues without prejudice. Instability in care or inappropriate treatment from GPs could precipitate crises in service users' lives:

> 'I am sick of doing it [transferring to another doctor], I keep transferring my file, I transferred it to [a nearby town]… and he cut me off morphine and then I tried to kill myself and then I ended up going back to my previous doctor

and he said that he wasn't qualified enough to handle me and then I went to [another] doctor and he is just, yeah doesn't cut it either but I dunno, don't know where to find a doctor who can look after me.' (#54, male)

Service users were looking for GPs who were not only sympathetic to their needs but who could also demonstrate competence in dealing with drug and mental health related issues. Many service users had stories of bad experiences with GPs who had apparently trivialised the impact of illicit drugs, drug treatment or related mental health issues.

'I have recovered in three months [according to my doctor]. I've got my colour back so then I am all right to go back to work. This is my GP who just thinks there is nothing wrong with me. Never mind the fact that I have just spent three years of my life, I mean all that time I spent in hospital, thinking I am going to die, had two breakdowns, suicidal, all this stuff um, and [he] just thinks that everything's all right… I have a problem with this and I am trying to explain it to him and he thinks I am all right, 'cause I have got colour back in my face.' (#54, male)

It was common for service users to report that it was difficult to get GPs to attend to general health problems without those problems being automatically regarded as related to drug use. Many felt that their experiences of physical discomfort or pain were belittled or ignored by their GPs:

'"Oh, it's all the drug use", y'know? "It's just because you're on drugs, honey. That's why you've got these problems now", and it's just really degrading. Like it's kind of devaluing how you're feeling right now. You can say, "I'm not using now" – I have had that GP, because I've had bowel problems through using speed for all these years, and he says, "Oh, it will clear up", and I feel like saying, "It's been over a year, when the fuck does it clear up, buddy?", y'know?' (#75, female)

'I went into the doctor and just because I was having some difficulties breathing which is another medical problem I have got, he automatically thought it was drug related.' (#49, female)

Service users often found that GPs involved in their drug treatment program would not treat any other conditions until the drug treatment was seen to be completed or stabilised:

'…when I finished on methadone the last time, all of a sudden he was interested in my health needs. Still never mentioned the hep C but I had really serious um gynecological problems that he just wouldn't even look at until I came off methadone and then all of a sudden it's like "oh", y'know and, y'know within a few months of being off methadone, all of a sudden I had all these referrals to gynecologists and stuff like that, stuff that he wasn't doing before that.' (#30, female)

For these reasons, service users expected that GPs would always see drug dependence as their primary health problem, to the detriment of dealing with other conditions.

4.10.2 Disclosing drug use within general practice

The degree to which service users were prepared to disclose private or intimate aspects of their lives (including their involvement in illicit activities such as drug use) was dependent on the quality of their relationships with their GPs. Some service users consulted their GPs for an outside opinion on the drug treatment they were receiving at a drug and alcohol centre. Others tried to reveal as little as possible, even to GPs who knew they were engaged in a treatment program. Many did not disclose their problems with illicit drugs or their involvement in drug treatment to their GP at all. In the cases where service users felt that they could consult with and disclose fully and freely to their GP, they often identified these consultations as the most helpful and important aspects of the ongoing care and treatment they were receiving.

In order to avoid discriminatory treatment, service users often set up their own network of providers who were not aware or in contact with one another and withheld information from GPs who they did not think could deal with their drug-related issues:

> '…the moment they find out you're a user, they think you're a pill head as well.' (#11, male)

> '…nothing that you say after that will be taken, it will always be taken with a grain of salt, or, um, yeah, it really changes the whole relationship and a lot of doctors don't want drug addicts in their surgery, they just don't want them there. Because they scare off the other patients, I guess.' (#51, male)

> '…if I decided that I had mental health or other problems, a gangrenous toe or something then I would be inclined to go somewhere else and go to a doctor which I wouldn't mention drugs at all to so I could not have to face all that and not have to be another patient, and I think that's really common from what I have seen of most drug users, you have your drug doctor, your health doctor, your prescribing doctor, your treatment doctor...' (#45, male)

> 'I basically find myself in a situation now where I have um several doctors. One I can tell the truth to, um and he knows everything and the other one I go to like, y'know if I cut my leg or something minor repairs like that, and whereas before, um [my doctor] had my entire medical history. He knew everything about everything and it's like, I just know that the doctor I go to for um normal medical things and what have you, would not, well he just wouldn't treat me the same as he does now. And that can impact on my um health care which I think's ridiculous, but that's, it's just a fact. I mean, they've got their reasons and what have you, I don't particularly agree with them but um, y'know, it's a fact you end up lying to doctors.' (#11, male)

The use of multiple doctors was something of a dilemma for service users who had found it was a way to overcome discriminatory treatment, as they recognised that a single GP with access to all their medical information would have a better overview of their overall heath and wellbeing.

Service users who found a GP who was more than just 'the writing hand' for their drug treatment-related prescriptions, and who could provide general health care services as well, were generally very positive about their relationships with GPs. Good relationships capitalised on the one-to-one nature and continuity of the relationship, and were marked by trust from both parties. These were generally longstanding relationships. Typically these relationships involved a family doctor who knew and understood the service user as well as understanding the problems he or she faced. These GPs were described as more personal, flexible and responsive to the needs of service users in that they treated 'the whole person' and considered facets of the service users' life beyond drug use or drug treatment. Those GPs described as 'fantastic', 'fabulous' and 'indispensable' were described this way because of their attitudes to the patient rather than specific expertise in the field of drug dependence or mental health:

> 'I'm very lucky in that I've got a GP who is really easy to talk to and who's very understanding about mental health issues. He has been fantastic; he actually has made a list of psychiatrists for me to contact but they all need to be paid and I can't afford that. So I'm just sort of making do with him… He's very personal and you can talk about really intimate stuff with him… I'm so relieved I found him; if I didn't have him, I don't know what I would do. Y'know, because you know it's truly life-affecting, having psychiatric issues. It affects everything your friendships, the way you work.' (#72, female)

> '…she looks after her patients, she knows what's best for me and she may have bent the odd rule here or there – she might but she's not the kind of doctor you'd go to for drug substitutes at all… She's wonderful. She's looked after me very well. She trusts me and I trust her. I tell her everything and things she doesn't want to hear then she tells me not to tell her any more [laughs]. She knows when to tell me to stop. She sticks by her fucking Hippocratic oath. She looks after me and does what's best for me.' (#68, male)

> 'Um like I said that [my doctor] was quite a big help, I talked to him for an hour sort of thing, it wasn't just about what treatment I'm on or I should be on… we talked about general things. Like I said he is probably the only one who has been any significant help to me. And he's probably, not the psychologist, but he has a lot of experience.' (#50, male)

Some service users said that their GPs had educated themselves about methadone and other treatments for drug dependence, even though they were not providing that treatment. In a number of cases service users said that their GP had spotted their drug problem before they sought treatment. In other cases, GPs were often the first people to suggest that service users' mental health problems might be distinct from their drug problems.

4.11 Complex vulnerabilities

In talking about their experiences of drug treatment and mental health, service users described other aspects of their lives that adversely affected their ability to engage with

treatment. These included, but were not restricted to, poor housing conditions, restricted income and debt, having a criminal record, managing the effects of hepatitis C, family issues and relationship problems.

The structure of service users' lives was often extraordinarily fragile, and increases in stress or pressure in one area could set off a sequence of crises. In relating how he ended up in debt and with an impending gaol sentence, this participant described the compound or domino effect of complex vulnerabilities:

> '[I was] trying to keep on top of everything and then I had a bit of a breakdown – my Dad died, I got kicked off the methadone program and I broke up with my wife and moved away from my kids and what else happened, I got kicked off the dole.' (#2, male)

Many complex vulnerabilities were deeply interwoven, complicating the potential for progress in drug or mental health treatment. For example, service user accounts of depression and anxiety implicate poverty, homelessness and loss of the custody of children as exacerbating factors. Service users therefore learnt to negotiate many agencies and services separately particularly when these services were reluctant or unable to engage with external, albeit related, issues.

Service users described complex life problems that were unlikely to be resolved quickly or that tended to be enduring or recurrent. Drug treatment itself sometimes became another 'complex vulnerability' that service users needed to manage. Service users often needed to be proactive to access services and agencies, and had to be able to sustain commitment and motivation over extended periods of treatment. This motivation could be undermined by poor service delivery, the effects of treatment, and related depression and anxiety problems.

Illness, a sense of futility or hopelessness, and suicidal ideation were among some of the issues that service users described as affecting their ability to participate in treatment. Problems in attending or participating in treatment could then complicate relationships with service providers or agencies and could have significant ramifications:

> 'I didn't end up applying for Centrelink 'cause I thought I was going to die, so I thought who cares, what does – it doesn't matter about being paid. So then there was a whole year, nearly a whole year without being paid at all so I got out with no money, all these debts and ah, I mean I've got a mortgage ah yeah, so yeah, everything was getting to me. I just wanted it to stop.' (#54, male)

Although it was commonplace for service users to report periods of crisis related to drug use, mental health or related issues, participants described not always being able to locate or access the agencies and assistance that they needed.

> '…there are avenues there [for assistance] – but it's not stuff that's told to you. It's stuff you have to find out for yourself through panic and asking everybody, "What the fuck am I going to do?".'(#67, male)

Service users suggested that even when their situations were desperate, this did not guarantee access to crisis support. Some suggested that people expected drug users to be able to cope with homelessness and poverty. One interviewee described the response of a drug treatment service counsellor as follows:

> 'I was homeless, my son and I were living in squats and everything last year and it was, "Oh, well, you'll survive, I'm sure. You're a tough one. Off you go, you'll be right. Do you want to go and up your dose a bit?".'(#70, female)

Mental health problems among service users appeared to be compounded by poverty, unemployment, homelessness, isolation from family and sometimes also by difficulties in accessing treatment and support services. As more than one participant explained, it was lucky they had turned up to participate in the study – if they were having a 'bad' day with depression they would not have been able to face anyone. Yet despite these problems, service users made great efforts to remain upbeat rather than despondent. This was highlighted by way that they laughed off or made jokes about repeated incidents of injustice, institutional indifference or needless hardship, suggesting that despite adversity, drug treatment service users have resources to draw upon and are generally determined to get on with their lives.

4.11.1　Housing

The majority of participants in the service user arm of the study were in relatively stable accommodation, most commonly private rental accommodation (57%) or public housing (27%). A substantial minority of service users were in temporary accommodation such as boarding houses, hostels or refuges (10%). Two participants (3%) were homeless when they were interviewed for the study.

The stability and quality of accommodation affected service users' ability to participate in drug treatment, to manage their mental health, and to address other challenges in their lives. Those in safe, comfortable and secure accommodation described a more stable footing from which to participate in treatment and to address other issues, such as supporting their families:

> 'I think now too, now that we've got a place to live and it's ours, that's made a hell of a lot of difference to [my son's] attitude too, because we're stable now. You know what I mean. Being unstable is a very hard thing to cope with, especially for young kids. He could see my frustration – no matter which way I turned, doors were being slammed in my face all last year and just the frustration of it all! You know? And I really hadn't done anything wrong, all that was going on was that I got sick.' (#70, female)

Those in unstable, unsafe or poor quality accommodation reported adverse effects on their general wellbeing, their ability to attend or participate in treatment, and their mental health status. Single men in particular seemed to face particular challenges in remaining in stable accommodation or in trying to access crisis accommodation or public housing. For both men and women, being in drug treatment could be a barrier to accessing temporary accommodation, while drug user organisations were seen as useful sources of information and support in accessing alternative accommodation:

'I had a whole lot of problems with, you know, falling behind in the rent and stuff, I was on the street, that's when I slashed my wrist… I had just been kicked out of the place I was at. Um so then I was [in] homeless shelters and stuff for a while, three months and… one place um, I got sick of the rules there and had a shouting argument and got thrown out, um and then I went to [a charitable organisation]… and they had a thing where you couldn't take any methadone in there for some strange reason. And they did a room search one time and found an empty methadone bottle and kicked me out of there. But by that stage, um I went and saw the housing commission and I was eligible for um… you know, they'll give you a leg into a place once a year or something. And I was eligible for that, so that's how I got into where I am now.' (#4, male)

'I found myself the housing. There's not a lot of housing for a single man – unless you've got a wife and kids it's very difficult because you don't seem to be… I don't know, you're seen as not as needy as a woman on her own perhaps. That's the way it's perceived. So no, there's not a lot around, so it was a matter of asking friends. Actually it was through friends at [the drug user organisation] saying "I've got a place through this community housing thing. You go and fill out a form, blah blah" and wait six months.' (#67, male)

The two participants who were homeless at the time of the study, both single men, reported difficulties in accessing health services, welfare and drug treatment in particular, and in maintaining their personal safety. Other participants had also experienced homelessness, and faced challenges in maintaining stable accommodation or coping with the poor environment in which public housing was often located:

'I've been on a list for a while and lived in boarding houses and whatnot. At the moment I'm just sort of um in a spare room in a friend's housing commission, but that's really bad 'cause every couple of months he has a spack attack and he gets really black moods and he's manic depressive sort of person, gets the black dog.' (#2, male)

'I used to go for a little walk in [my] area – it's not very safe but um I'm currently getting help with transferring my [public] housing um, the lady's um, she's helping me to get a transfer and it's been four years um also the area that I live in, things have happened to us whilst living there, that's sort of got on top of me as well.' (#28, female)

'…they ended up giving me a [public housing] house in 2003 when my baby was born and I moved out to [a suburb], got my house out there and that's where all my friends are, all my other drug user friends. They're into the [treatment centre] and that there but, there's still other people that's not in it out there. And it's pretty hard for me to be out there where it all is and that and… just that scenery out there has made me go downhill.' (#34, female)

4.11.2 Debt

It was common for service users to report that they had had problems with financial debts, most often as a result of trying to manage being drug dependent, in other cases

from losing a job or not being able to work, or from gambling, theft or robbery. At the time of the study, the vast majority of service users were supported by government welfare payments (88%). After paying for essential items such as food, rent, being dosed and utility bills, most service users had little money left for other activities:

> '…at the moment I'm paying so much rent which takes the majority of my cheque – like $180 a week for a flat… when I've paid for $30 to the clinic, including bus fares, out of the $40 I have left, I have $20 to live on.' (#69, male)

This could generate a sense of helplessness or frustration and a number of participants suggested that they would like to undertake more paid employment to break out of the cycle of poverty and lack of opportunity. However, the constraints of participating in drug treatment, particularly the routine of having to attend methadone clinics at inconvenient times for dosing, meant that it was difficult for participants to see how they could participate in the workforce, even if they were offered a job opportunity. The frustration felt by participants is captured in these quotes from men who wanted to get their driver's licences back in order to look for work:

> 'In some ways there's no way that you can sort of help but get depressed, you know like um… [I] go for my methadone, y'know, haven't always got money so you jump on the train, that's a $200 fine, y'know and that doesn't go away. Y'know, you don't see it until you want to get your licence and then all of a sudden there's all these $200 fines there and stuff that have added up and if you, y'know you want to get your [driver's] licence there's um, that's all gotta be gotten out of the road first… the State does a really good job of keeping you poor, by not letting you get off the, by making it very difficult of getting off the ground floor of your life.' (#4, male)

> '…if you go to the RTA, not the RTA, the State Debt Department, if you say, "Look, I'll start paying off me fines at so and so, y'know what I mean, every fortnight, 20 or 30 bucks a fortnight, give us me [driver's] licence back". And like, being realistically, I don't know if someone said this to me or if you've thought of it before but, like if I went in there and said, "Look, RTA, you give me my licence back for three months, I'll go and get a job, right, if I don't get a job by those three months, you take the licence off me, but if I do get a job, then I'm in gainful employment, I'm not on the dole right, then I'm not using, so then well I don't wanna steal your car or burgle your house". So why not, y'know what I mean, like why not give a person a go?' (#5, male)

4.11.3   Criminal justice issues

Because the buying, selling and consumption of illicit drugs are criminal acts, illicit drug users inevitably become implicated in criminal behaviours. Dependence on illicit drugs, particularly heroin, was considered by numerous service users to precipitate, and in some cases necessitate, other crimes in order to fund the purchase of drugs. Becoming involved in drug-related crime also increased the chance that service users would be victims of violence and assault.

Numerous service users reported seeking treatment after they had reached the point where they had no access to illicit drugs except through criminal activities. A substantial minority of service users first received drug treatment in prison or as a compulsory requirement of a court diversion program.

Even if they had avoided criminal activity other than illicit drug use itself, service users could find that engaging in treatment labelled them as 'junkies' or criminals. The stigma attached to any aspect of illicit (and particularly injecting) drug use transfers to drug treatment programs, seriously limiting opportunities for service users to seek employment or participate in other aspects of everyday life. Registering for drug treatment could also have very worrying and tangible consequences for families, precipitating welfare intervention and the potential loss of custody of children.

The criminality associated with illicit drug use blurred the boundaries between illicit drug use as a criminal justice issue and drug dependence as a health issue. A small number of participants reported developing drug problems in gaol. For some, participation in crime and drug dependence developed together. For many others, the financial cost of maintaining a drug 'habit' led them towards crime.

Even for those in drug treatment, there was still some temptation to turn to criminal activity to boost income. Most service users reported that their income was extremely limited or insecure. In some cases this situation underpinned instances of petty crime such as fare avoidance on public transport, shoplifting and (in very few cases) the selling of takeaway methadone doses:

> '…they wanted to evict me just before Christmas because I was having a really rough time and they were cutting me off my pay and everything so I was really stressed and y'know like, I, Christmas is more for my sisters, y'know like that's what I was worried about, I wanted to give them something for Christmas so, it was a lot on my plate at the time and, to be honest I went shoplifting and it wasn't for drugs, it was shoplifting for presents. And I got caught.' (#31, female)

4.11.4 Hepatitis C

Service users reported that hepatitis C infection was often diagnosed on their entry into a program of drug treatment or, in a minority of cases, prison. While service users with hepatitis C do not experience discrimination in drug treatment services in the way that they encounter it in other health services, counselling around hepatitis C diagnosis was commonly described as casual and insensitive. One service user said that they had been given the blood test results diagnosing hepatitis C by a clinic receptionist.

Service users with hepatitis C did not demonstrate an in-depth knowledge of the infection, had little confidence in symptom recognition, and little awareness of treatment options. Service users who had hepatitis C had a general understanding about healthy eating and lifestyle factors and in bigger treatment centres regular liver function tests appeared to be encouraged. For others, liver function monitoring was erratic. Many service users appeared to be confused about their hepatitis C status (the progress of their condition, what type of infection they had, and whether they might have 'cleared' the

virus), and this situation was aggravated by conflicting information and attitudes from health professionals.

No service users with hepatitis C were currently receiving treatment for it at the time of the study, and few were discussing treatment options with their drug treatment providers or other professionals. This may have reflected the focus of drug treatment services on stabilising drug-related issues, but it also reflected a lack of interest among service users (and possibly providers) to explore treatment options for hepatitis C. Those without obvious symptoms or liver deterioration did not have a pressing interest in treatment, and many had heard concerning stories about the side effects of hepatitis C treatment. In particular, for those coping with anxiety or depression, the increased risk of depressive side effects under interferon treatment was a major barrier to treatment. Others were wary of being used as 'guinea pigs' for new hepatitis C drugs.

The few service users who had tried older interferon-based treatments reported challenging mental health side effects. Treatment was described as causing depression, mood swings and uncharacteristically aggressive episodes. In general however, because it was difficult for service users to distinguish between the symptoms of anxiety/depression, drug use, substitution pharmacotherapies or hepatitis C, it was difficult for service users to attribute any difficulties they were experiencing to hepatitis C infection.

4.11.5   Family issues

For some service users, negative or challenging early childhood and family circumstances were clearly implicated in their drug or mental health problems. Some service users described parents and siblings with drug or mental health problems:

> 'I was adopted to my aunty and uncle and ahh, my uncle raped me so I ran away and then they put me in a girls home, that was when I was 12, so that could have been you know the root of all my problems to begin with… I was in the girls' home then I played up there, I was supposed to only be in there for six to nine months and I played up because I didn't know whether I was going to go home to my real mother or not and I thought, "Well I'd rather stay here than go back to my aunty and uncle", and y'know face all that drama again. So I ended up staying there for about 14, 15 months in the girls home.' (#3, female)

Many service users talked about the difficulty in trying to maintain family relationships while participating in drug or mental health treatment. Some participants had become estranged from their families, often because of the shame and embarrassment attached to illicit drug problems. Others described their families as supportive and understanding but even for these participants it was difficult for their families to understand challenges faced by those in treatment:

> 'I didn't get the support that I needed cause my parents aren't really on the same wavelength as an addict and I couldn't get the support that was needed, only a roof above my head.' (#44, male)

> '…you have to take a support person in and my dad was my support person and do you know, my dad he just doesn't want to listen and um, doesn't talk

about feelings and stuff, and dad's like, "It's just stupid, I can't understand why she uses drugs". And [the] doctor was agreeing with him.' (#48, female)

'…my father, he actually doesn't know about the [buprenorphine], he thinks I am recovering on my own. I talk, I have the support of my family, they know about my depression and my anxiety and all that um, no-one knows about the [buprenorphine], so I just keep that to myself.' (#54, male)

Many participants were keenly aware of the burden their drug problems and treatment put on other family members. Service users who were parents were worried about the negative effects on their children of having a parent stigmatised by drug problems:

'…my family's supportive but I am really stretching it at the moment y'know? I am staying with my mother and she's not entirely well herself, she is prone to anxiety and has low self-esteem and that sort of thing but ah I am doing her head in.' (#39, male)

'I feel like I should be supporting them [my parents], which I try to as well 'cause they're older, and I get a lot of guilt 'cause I have sort of damaged them through my addiction.' (#47, male)

'…when [our son] was pre-primary and grade one, he used to get invited to parties with all the kids and stuff, but I think that someone from, like one of the mums at the school has seen my partner picking up at the chemist and went "oh, y'know, they're on methadone and oh they're junkies and whatever", and [our child] hasn't been invited to a birthday party for the last three, three or four years.' (38, male)

4.11.6   Relationship issues

Intimate relationships with partners were very important to many service users. A few described sustaining relationships with non-drug using partners, but more commonly service users described current relationships with partners who were also in drug treatment. Trying to maintain a relationship was reported as a strong driver for engaging in treatment, but participating in treatment could limit the potential for new relationships:

'…it is really hard to have a relationship with someone who doesn't use – any sort of relationship – because the media's given the idea that drugs are really, really bad and, y'know, you can't be a functioning human being if you are on them. So that person is always really worried about you because they care about you! They don't know that that it can work.' (#53, female)

Confidentiality was an issue for service users with past or current partners at the same treatment service. Some participants reported feeling threatened when their case worker referred to things they knew about their relationship from their partner. Service users can be reluctant to use facilities where they may encounter those who have a history of intimidating or threatening them:

'I left my ex and it was too unsafe to walk in the same surgery as him, he would find whatever he could and attack me with it.' (#55, female)

Former or current drug users were often seen by service users as the only people who could really understand what it was like to deal with drug problems. Precisely because they have similar issues, other drug users could be both sources of support and potential problems for service users. Erratic behaviour of drug using partners could generate problems with tenancies, the police and other authorities, including treatment services.

Some participants had decided that getting a drug problem under control or participating in treatment required them to end relationships or cease social contacts with others in drug-using or drug treatment milieux. This could be difficult to undertake and could also render service users isolated and reclusive:

> 'It's taken so much away from me in the last eight to ten years because I was very social, had a lot of things happening at the one time and stuff, and I started to feel so ashamed, not that I did bad things to people but some people had helped me a few times and I thought, "I don't want them to see me having to go through this again", so I just faded away from them. And other people… I sort of had a public profile; people I didn't know knew me and a lot of the stuff I was doing. That's when I started to hide. I moved back to my parents' place and would just sneak into town to get dosed and then sneak home. I've got a handful of friends that I've seen all through that. I kind of imagined for a long time that, um by not seeing a lot of my friends, I would be not destroying those relationships and then, one day when I reach the level of perfection or whatever (and I've got this list in my head, when I've got a car and this and this), then I might re-emerge.' (#60, male)

> '[The doctor I see at the moment] is an antenatal doctor so he's more for [my baby] than me but yeah, but no I don't have anyone that I regularly see. Not even my friends any more.' (#55, female)

4.11.7   Institutional and inter-agency support

A return to and maintenance of 'normal life' that is generally defined in terms of the stability of housing, relationships and work, is the commonly voiced aim of service users. However treatment services and related agencies seldom provide the practical support necessary for users to return to normal life and maintain work, family and other relationships.

The areas that were most directly affected by existing features of treatment services concerned barriers to employment and to caring for children. Service users were often very clear about the type of additional support that they occasionally needed, which was generally practical and often about dealing with one-off situations, e.g. someone to provide advocacy or information about a specific legal or housing situation.

Service users were vulnerable to a system that could be arbitrary and lasting in its judgments – with regard to losing housing, and losing child custody in particular. Once these problems were encountered, finding out how to engage with the system and rectifying issues was very stressful and frustrating. Many service users had found themselves caught in a number of systems – social welfare, justice or health – that they had to navigate simultaneously.

The treatment centres which did provide support for aspects of the users' life beyond that of medication and detoxification were highly praised in these interviews. Accessing more general services for drug users (and also needle and syringe programs) led participants to seek treatment for dependency in some cases. For instance, many service users first accessed their local drug user organisation when they were seeking help with other areas of their life, e.g. references for dentistry, work or accommodation, and then found out about treatment programs in their local area.

The importance of inter-agency referrals was emphasised in accounts where a prompt intervention had arrested the sudden downward spiral of events that were all too familiar to many service users:

> 'I've seen it happen with certain women in my group who have had huge and horrendous relapses and suicide attempts and kids taken away and everything's gone from being OK to back living on the street, no kids, no life, totally completely crap. Yeah, and through a network of different agencies gathering around and lifting that person up, getting their lives back together completely.' (#74, female)

However service user accounts overwhelmingly described a system of referrals that was often inconsistent, slow, and frequently failed to follow up or give the service user any feedback from the consultations they had attended. If referrals were not made service users could feel that the service providers involved had given up.

Barriers and Incentives to Treatment for Illicit Drug Users with Mental Health Comorbidities and Complex Vulnerabilities

Chapter 5:
Service provider interviews

This chapter presents findings from interviews with professionals who provided services to people with co-occurring drug and mental health problems. This included drug treatment specialists, mental health professionals, and staff from referral, support and advocacy services (notably drug user organisations). The material presented here explores the challenges posed by co-occurring drug and mental health problems to service providers, including difficulties in diagnosis, supporting consumers and implementing effective treatment models. It also explores providers' opinions on how comorbidity should be addressed within treatment settings, and how consumers cope with having a 'dual diagnosis'. Ideal treatment models and barriers to treatment are also addressed.

5.1   Relationships between drug use and mental health

This section covers the issues arising in service provider interviews regarding the relationships between drug use and mental health. Two main themes were apparent in this area: difficulties in diagnosing co-occurring mental health and drug problems; and relationships between mental health and drug use services.

5.1.1   Difficulty of diagnosis

Participants spoke about the difficulty in attributing a service user's presenting symptoms to either drug use or mental health problems, noting the overlap of the effects of each on the consumer's experience. One participant from a mental health service recommended the observation of service users for longer periods to 'get an accurate idea of the mental health status' of those presenting for treatment:

> '…how much of their presentation is a primary result of an affective disorder and how much because of their self-medication? How much of their presentation is either related to drug withdrawal or the effects of the drug? So someone that is using a lot of speed for example and then becomes very anxious and paranoid, you know, is that related to their speed use or is that related to an underlying anxiety disorder? It's incredibly difficult to sort out.' (#1, drug and alcohol service)

One participant suggested that when service users try to express their mental health symptoms this is seen as drug-seeking behaviour and is 'invalidated' by professionals. This can mean that consumers do not talk about their mental health, or lie about or exaggerate their experience to obtain assistance.

Some participants spoke about the interplay between treatment for both drug use and mental health exacerbating underlying depression and anxiety issues. For example, inappropriate treatment of depression with benzodiazepines was seen to perpetuate depression. The 'unrealistic' goals of a consumer entering drug treatment (in this example, drug substitution therapy) was seen to lead to depression when the 'honeymoon period' of treatment was over and the service user realised that treatment was likely to be long term. Also, the possibility of being 'outed' as a person undergoing drug treatment in a regional area was described as leading to anxiety and having a 'disastrous impact on their quality of life and how they're perceived by other people'. Some providers said that the people they saw in treatment used illicit drugs as a mechanism to 'deal with trauma

in the[ir] life'. Hence the cessation or reduction of drug use while in drug treatment could lead to service users 'struggling for a little while until they begin to develop some self-coping mechanisms'.

One general practitioner indicated that he thought the depression and anxiety reported by a large proportion of his patients 'disappears' once service users have stabilised on a drug substitution therapy such as methadone.

There was general agreement among the interviewed providers that self-medication is a central component of living with dual diagnosis, i.e. that illicit drug use is seen as a way to manage symptoms of mental health problems:

> 'And, as you know, people get this funny mindset that, if they can put themselves into a drug-induced fog, then those anxiety and depression issues don't surface as bad. I think a lot of it's actually about people's inability to deal with their anxiety and depression.' (#2, drug and alcohol service)

Self-medication was seen to complicate the diagnosis of mental health problems. In terms of implications for treatment, it was noted that when self-medication with illicit drug use is removed or reduced in treatment, then it is a priority for providers to address mental health problems and initiate antidepressants or other treatment or supports to ensure that 'people can proceed with change in a way that's quite safe':

> 'For many, they're coping with enough stuff in coping with the drug use and mental health services would send them off and not offer them a service until they take themselves off drugs and get treatment for substance abuse. Then they can stabilise their mental health… I think that's quite dangerous. People can use drugs and whether it's quite harmful or whether it's quite simple to stop them, to take that crutch away might not be the most effective way to give them treatment because they're very vulnerable… so they're more vulnerable to attitudes around them to their coping mechanisms. They might just be working out what ways they can use as coping mechanisms… It's not like we're advising people to carry on with substance use either but it takes more than that before people can proceed with change in a way that's quite safe.' (#3, drug and alcohol service)

5.1.2 Falling between the cracks of mental health and drug treatment services

The 'bounce' of service users between drug treatment and mental health services was acknowledged and described by service provider participants. That is, service users were refused treatment by mental health services until their drug use was under control (or eliminated) and service users were also refused treatment by drug and alcohol services until their mental health problems were addressed:

> '…there's the age-old cry that drug and alcohol services say, "This client's got a mental health issue", and mental health services say, "Yeah, but we're not dealing with them because they've got a drug and alcohol issue", and then it's this sort of classic bounce of the patient between the two services where

> there's a sense that neither is either necessarily willing or able to take on both sides of the coin and they end up falling through the hoops.' (#1, drug and alcohol service)

> 'Or they are assessed by mental health services and they think they need to deal with their alcohol/drug problem first before they provide any intervention. So there's a lot of to-ing and fro-ing.' (#9, drug and alcohol service)

The impact of the 'bounce' between services was described as consumers being denied access to services in terms such as 'go away, stop the drug use and you'll be all right'. This could mean that service users felt they had no option but to lie to obtain the assistance they wanted (such as denying a psychiatric history to AOD services) or they could become frustrated and leave the therapeutic system.

5.2   Use of clinical language

This section describes the issues arising in service provider interviews related to the use of clinical language. Three main issues arose in these interviews. First, service provider participants discussed how they understood or used clinical language in professional contexts. Second, service providers outlined how they used clinical language in interactions with service users. Finally, service providers commented on the ways that service users described their own experiences of mental health and illness in clinical settings.

5.2.1   Definitions of dual diagnosis and comorbidity

There was a range of uses among service provider participants of the terms 'dual diagnosis' and 'comorbidity'. Comorbidity was 'reserved' by one participant to describe more severe recurring disorders such as schizophrenia or bipolar disorder. Comorbidity was also used to describe co-occurring physical conditions, social circumstances and material conditions ('HIV positive, hep B positive, hep C positive, homeless and poly substance dependent'). A similar point was raised in relation to dual diagnosis, with one participant stating that the clients of their service did not have dual diagnosis but deal with 'quintuplet or sextuplet type problems'. One participant felt that comorbidity 'means everything and it means nothing at the same time' and described efforts undertaken to 'standardise language so AOD services and mental health services actually talk the same language when they talk about mental health' (#13, drug and alcohol service). A representative from a drug user organisation was critical of the use of the terms comorbidity and dual diagnosis, explaining that the terms better described the organisation of services than the experiences of service users. This participant used an example of tobacco to question the assumption of *illicit* drug use as a precursor to mental illness:

> 'It's like, "Oh, these people are different because they're this", and… it's the… the dual diagnosis isn't in the person, it's in the structures that are set up to support the person. That's where the duality lies; it's because we're saying that drug and alcohol issues are different to mental health issues. That there's

a duality there; it's not, you know the person's… not somehow unusual or different… or more broken than the rest…Depending on your jurisdiction, you know, somewhere between 65 and 85 per cent of in-patients in the mental health system use some sort of illicit drug and this is often like interpreted as some sort of causative thing, y'know? In any jurisdiction, at least 75 per cent of the in-patients smoke cigarettes. That's so far above community, y'know, levels and nobody suggests that cigarettes cause mental illness. It's quite obvious that the cigarettes are one of the coping strategies the person's got and I guess the same is probably true in a lot of the cases of other drug use. That if you don't feel that great a lot of the time, then maybe you are inclined to take a substance regularly, you know? If it makes you feel better for a while. Now, um, although no-one says that cigarettes cause mental health illness.' (#14, drug user organisation)

5.2.2   Use of clinical language with service users

Service providers generally opted not to use clinical language with service users but grounded discussions in the consumer's experience and perception of symptoms. Participants chose to not use clinical language as they perceived that, in general, service users would not understand it:

> 'Basically I've found, when we were talking about what you've noticed about the almost complete absence of clinical language or understanding of clinical language in a lot of people, y'know, that is a reality. When I'm talking to people, I tend to talk as much as possible in their own language… I think generally you hear people use comorbidity or dual diagnosis as clinical terms; it's not necessarily something that's used when you're talking to people. I'm more likely to be talking to people about, y'know, "If you're smoking an enormous amount of dope, let's just track where these other things are coming from and when and how it's affecting you and your mental health problem. That's if you want to feel better and cope better out there".' (#6, drug and alcohol service)

Although service providers spoke about using 'client-centred language', another participant described the need to educate other workers about acting as interpreters between mental health professionals and consumers. This participant felt that the use of clinical language was a barrier to consumers expressing their symptoms and needs and therefore prevented consumers obtaining assistance and treatment for mental health problems.

> 'In one of the training sessions I used to run on comorbidity one of the role-plays we did was actually as a rural worker acting as an interpreter between a psychiatrist and a consumer. Because, y'know, the psychiatrist asking someone about their drug use and not understanding the drug terminology; the psychiatrist talking about clinical language and the consumer thinking "What the fuck are you asking me? I don't know what you're talking about!" so it really wants some interpreting.' (#7, drug user organisation)

> '…it should be more consumer-friendly because people feel really stupid, they feel ashamed. It just silences them and really shuts them down. It's really

interesting in terms of if you're using "people talk", the information you get is completely different to what a psychiatrist might be trying to evoke from a person, using clinical language.' (#7, drug user organisation)

5.2.3 Consumers' use of language for mental health issues

Providers noted the disparity between service users' language and narratives around drug use compared to those concerning mental health. Participants felt that service users did not have as detailed a language to describe their mental health experiences compared with the rich narratives they employed to describe their drug use. Providers thought that the lack of mental health language indicated a lack of familiarity with the mental health system and a fear of the stigma of a mental health diagnosis. One participant felt that there was 'more language' around depression than anxiety, i.e. that consumers could talk more easily and expansively about depression compared with their experiences of anxiety:

'I don't think the degree of confidence about what it means or what's appropriate or, y'know, everybody else has got Hep C, everybody else has been on and off methadone, everyone knows a story about somebody on bupe or naltrexone. Nobody else sort of talks about being on SSRIs or tryptonol or… and I don't think there's as much as an understanding or a confidence or… what is the word I'm looking for... a sense of sort of ownership and power over what it means, all the sort of different medications or treatment might mean in the mental health area as much as drug treatment.' (#1, drug and alcohol service)

'Yes, well the other aspect is we were working a lot of the time with people who'd had mental health problems for some time but had not addressed them. When they came into the situation, therefore, they weren't familiar with the questions they were going to [be] asked; they didn't have the same language to answer them or understand them in the first place. They were probably fairly fearful about mental health, y'know, being given a mental health diagnosis and it would take some time to get to the point. Yeah, it would delay it considerably longer than the wider community seeking assistance…Also, I think, regardless of all the work that's been done in addressing stigma and education programs on mental health etc, basically people in the community are scared of it. So if you try and talk to somebody about the fact that you're experiencing mental health problems, they're more likely to say, "Look, I don't want to know about this; just leave me alone", so people learn very quickly not to talk about it because nobody wants to know. The consequences of that are often that they don't develop the language, they don't develop a positive and lucid way of talking about their mental health experiences because of this cut-off and not being allowed to. And then the consequences of that, about being open about drug use – yeah, there's always a reticence about discussing that.' (#5, drug and alcohol service)

'Anxiety is hard to comment on because it's really hard to… I mean, I think there's lots of people who come here that are very anxious about themselves but I find it's hard to know how anxious they are and so I find that hard to comment on. But depression is easier to comment on because people will state

that they know they're depressed or that they're feeling bad or that they've tried to kill themselves lots of times. So it's quite easier to pick the people, it has more language around it.' (#6, drug and alcohol service)

One participant outlined that the difficulty in being treated for dual diagnosis meant that to take on a mental health diagnosis led to restrictions on opportunities for treatment. People who are 'naive' to treatment may be more likely to reject mental health labels compared with those who have a longer history of engagement with treatment. An alternate view was posed that those who had experienced a lot of different services or interventions may have a better understanding of the interplay between their illicit drug use and mental health. However, the understanding of mental health gained by exposure to drug treatment was described as not necessarily providing sufficient insight for effective treatment or 'what they need to do to remedy it [mental health]'.

5.3   Relationships between drug treatment and mental health services

Relationships between the drug and mental health sectors were often described as being dependent on resources. In particular, it was noted that mental health services were poorly resourced to look after existing case loads or to take on 'difficult' consumers with substance use problems. Participants used terms such as 'frustration' and 'ongoing tensions' to describe the relationship between sectors:

> 'We do have links with Mental Health but it's a constant struggle [laughs]. And probably really our links with Mental Health are in terms of acute presentations – as in someone [is] admitted who is either suicidal or very unwell with psychotic symptoms.' (#4, drug and alcohol service)

In some cases, service providers saw no option but to act as 'gatekeepers' to mental health services because of limited resources. Participants described limiting the number of referrals they made to mental health services in their area to strengthen the possibility that they had access to services for the most severe or difficult cases.

> 'You have to restrict it to the people who are critical – look, y'know, they're short of staff; they're slightly overwhelmed. They're not sitting down waiting for every referral from us.' (#2, drug and alcohol service)

> '…it's like the best psychiatrist in town, you know, we don't like to send the average patient to him or her because they're busy and because they're expensive and because we want to keep them for our difficult patients. That's just one of the conundrums of… it's like in the building industry – y'know, do you call in your best engineer just to fix a doorstep? But then, if you've really got a dicky job, then you need him or her to come in and do the job. So we're still in a difficult area where there's certainly a shortage of all specialists so we don't refer people lightly, unless we really feel that we're failing and somebody else has really got the talents that our patients need.' (#8, GP)

Other participants from drug and alcohol services suggested that their geographical location, specifically inner Sydney, disadvantaged their access to mental health services for dual diagnosis clients because this area housed a disproportionately high number of people with severe mental health problems:

> '…and what would be considered acceptable behaviour in the main street of [the inner city suburb where the service is located]… a standing joke with staff is that if you really want to get somebody scheduled and some kind of treatment, there's no point in trying to get a crisis team here. Put them in a taxi to [a neighbouring suburb] and they'll be picked up immediately. You know, routinely I look out of the window and I see people screaming in the street, I see somebody running down the street naked, I see somebody screaming at the brick wall, I see fights, I see somebody wailing in a gutter or … y'know? That's kind of, "Yeah, yeah, same old people", they don't even turn their head as they walk past it because that's become part of the public face of [this suburb].' (#1, drug and alcohol service)

Other participants discussed the need to work towards developing and fostering a culture or indeed a policy of willingness within mental health services to work with dual diagnosis clients:

> 'It's more a battle of winning people over, I think. There isn't a policy that specifically states that. There's a lot of willingness to work with it effectively and there's been a lot of work done with the treatment agencies that have actually worked together quite a lot over the last five years or so.' (#5, drug and alcohol service)

> 'So when I do a survey of our mental health resource people, some of them did mention that some other staff do have negative views on dealing with people with dual diagnosis disorders and that they should be referred to mental health services straight up. So I think there is some element there but I don't think it's the majority of people that feel that way.' (#9, drug and alcohol service)

> 'What the problem is, is the willingness to treat people and I've had a long time to work out our differences and mental health works on that basis (as I said before) where they're really looking at um, seeing people to diagnose them. And once that diagnosis is sorted, then working out how to treat them and get them to a steady stage or to cure them. Whereas with us, we have much smaller goals, much lower goals, much less altruistic goals. I think we're really looking to help people get through every day. We don't look to diagnose that they have got a particular type of problem; we look to help them with what problems they have and that's whether it's the social welfare, whether it's physical, whether it's psychiatric, whether it's… y'know, whatever. We know it's got the common bond of being exacerbated or created by the alcohol and drug or other drugs that they're consuming. And so obviously our first reaction is to want to try to get them, to cure them of that drug use. But we recognise that y'know, you can't do that instantly,

so the harm reduction model that we work on, says y'know, "If we recognise that you're as mad as a meat axe but you don't when we see you; and you're not at a danger or risk to anyone else in that madness, then we will just work with what the issues are that you bring and we'll gradually get around to the idea that you're mad as a meat axe and that you really need some assistance". And by engaging and developing that level of trust, we usually get the person in a little while to accept that what we can see they also have kind of known or felt, you know they accept it then and they start looking for where they can get that treatment that they need.' (#15, drug and alcohol service)

Other issues raised included the lack of feedback from mental health services after a referral has been made from a drug and alcohol service; the desire to refer a client direct to a community psychiatrist without having to go through an 'inexperienced' intake officer; and the desire to have a greater variety of mental health services which approach counselling in a 'holistic' manner and address complex issues in consumers' lives without limiting the focus to problems with illicit drug use.

A worker from a peer organisation described himself as a "bridge or interface between these two groups of agencies… that don't engage very well with each other", and a worker in an advocacy agency stating that in "90% of cases" their agency would be the link between drug and alcohol and mental health services. However, peer-based and advocacy services struggle to establish "credibility" in their relations with government-funded drug and alcohol and mental health services.

5.4   Ideal treatment models

Providers suggested that an important incentive to engage consumers in treatment for co-occurring disorders was the coordinated and integrated provision of services with a focus on consumer needs. Ideally participants suggested that drug treatment and mental health services and services for addressing complex vulnerabilities should be located in the same place. In addition, good liaison between services including referral and feedback was noted as an important incentive to treatment:

> 'So yeah, if people are going to be referred from one agency to another, it's not another walk across town or making another phone call, making another appointment. It can actually all be handled in the same place. And, you know, good liaison between clinical services and those services and cross-referral and excellent communication, that's helped enormously. Those sorts of things need to be… it's one thing to set those up but they can fall down. Particularly they can fall down pretty quickly unless you're really working at it... in my experience, it's one thing to have a couple of meetings and set things up. Unless you very assertively continue with that, it tends to drop away.' (#5, drug and alcohol service)

Providers saw the status quo of having separate services for different issues as reflected in the organisation of training and the professional structures for drug treatment and

mental health professionals. The 'polarised' nature of drug treatment and mental health services was seen as entrenched in funding streams and organisational cultures requiring significant efforts to achieve the levels of integration seen in, for example, the United Kingdom:

> 'So thinking about the actual environment of services that see these type of people instead of well, ok, drug and alcohol specialty doctors is now… you know, you get your chap who comes in [for] aversion training and psychiatry is over here and that's something different, therefore we've got two different specialty colleges and we operate in different ways and therefore we'll operate in physically different buildings through different systems. People are not going to go to multiple places in any one day to seek multiple episodes of help. It's much more likely to happen if it's made easier for them. So that would be one major thing [to improve].' (#1, drug and alcohol service)

> '[in the] UK where services are generally more integrated because you tend to find AOD services are run by consultant psychiatrists and staffed by psychiatric nurses. So the issue isn't as polarised. The Australian model tends to be that you have two different funding streams and you have different sorts of different disciplines working within different areas… I don't think the answer to this quandary is about specialist services. I think it's about changing, y'know, changing job descriptions, changing contract obligations, contractual obligations and outcomes so that each part, y'know, each service – whether you be AOD or whether you be mental health, y'know, – we can no longer say that, "Clients fit neatly into one of these two services", that we both need to be geared towards addressing both issues simultaneously. And it's about… it's not just about training it has to be at a bigger, y'know, a broader level, it has to be about changing job description forms, it has to be about changing contractual obligations from service providers so that, y'know, they can no longer turn away from this issue and try and bounce it across the table to the other service provider. I don't think, y'know, a third party coming in is the way forward. I think integration has to occur from both parties and how we achieve it; full integration is about changing job descriptions and changing what our contractual obligations are.' (#13, drug and alcohol service)

A number of issues relating to the ability of general practitioners to participate in the care and treatment of people with dual diagnosis were discussed by providers. The utilisation of general practitioners in areas of limited access to other mental health services was emphasised by some providers. These participants described how services could organise a GP liaison officer to facilitate communication between drug treatment services and GPs or to refer clients to GPs if psychoactive medication was required. One participant (who was a GP) argued that systems that manage service users with both drug and mental health problems should be centred on the notion of GPs as coordinators of care:

> 'If the patient is just treated in isolation without a GP, then the whole system breaks down.' (#8, GP)

5.5   Barriers to effective service provision

A range of specific barriers to effective service provision for mental health and drug use were discussed by service providers. The barriers ranged from structural issues such as lack of resources and beds, lack of workforce training and the organisation of separate drug and alcohol and mental health specialisations, to interactions between treatments for drug dependence and depression or anxiety. Other barriers identified by service providers included the stigma associated with mental health and the impact of complex vulnerabilities on service users' abilities and capacities to address mental health or drug dependence issues in their lives.

5.5.1   Mental health and stigma

As noted before, providers thought that the stigma associated with mental health had negative effects on treatment outcomes for people with both drug and mental health problems. For example, fear of a mental health diagnosis was described as resulting in service users denying symptoms or refusing to discuss them, in turn limiting the opportunity to develop a comprehensive way for providers and service users to talk about and understand mental health problems. In addition, stigma was discussed as a reason why GPs may decide not to get more involved in the care of those with drug and mental health problems:

> 'The two together really create quite a significant marginalisation…in many different aspects of their lives.' (#11, drug user organisation)

The fear of stigma and the reluctance of consumers to address their symptoms were perceived by some providers as leading to greater self-medication:

> 'The only thing I want to say is that clients who attend this service – which is probably a reflection of the general community perspective as well –there's such a stigma against mental illness and there's a lot of denial – and that's even in the broader community. But I think, if people are presenting to an alcohol and drug service, they don't really want to be told that they have a mental health problem as well and I think, because of the stigma that is attached, there is a lot of denial. So their mental health disorder gets very covered up by their substance use – actually medicating themselves by the illicit substances [for] their underlying mental health problem.' (#9, drug and alcohol service)

The issue of acceptance of mental health labels was discussed by service provider participants who noted the preference of service users to identify as drug users rather than as people with mental illness. One provider felt that a diagnosis of depression or anxiety was not as stigmatising as a diagnosis of psychosis to people with illicit drug use problems and indeed would provide a means by which they could see their use of illicit drugs as a normalised reaction to life stress:

> 'My sense is that [stigma] more relates to psychotic illnesses or to personality disorders. My sense is that once people… on average they've got a drug using career of some ten or eleven years, they're actually pretty OK about

talking about their drug use, potentially even OK about taking about being homeless and sex working. To throw in that, y'know, "I've got a depression" or something, I don't think there's additional stigma for these clients for something like depression and anxiety, certainly not for the females, perhaps more for males. But my sense (rightly or wrongly) is that, given all else that's going on in their life and all the other things that they self-report and are prepared to talk about, to mention that they think they've got depression at some level I don't think there's a difficulty and, for some people, that gives some sense of, "This is why my life is full of crap. There you go, there's a reason, that's why I'm a drug user. I was diagnosed with depression, that's why I self-medicate". That's almost sort of normalises some aspect of their situation… So yeah, I think that's actually different to some degree than the normal population. My sense is that there's more of a stigma for me in an office to say to somebody "Oh, I think I've got depression/anxiety" than it would be for me as a drug user, in the context of all else in my life to say "I think I've got depression/anxiety".' (#1, drug and alcohol service)

5.5.2   Complex vulnerabilities

The importance of complex vulnerabilities in the lives of people with co-occurring drug and mental health problems was widely commented on by providers, as was the effect of complex vulnerabilities on treatment experiences. For example, some providers saw the lack of holistic or comprehensive services that address complex vulnerabilities as forcing consumers to access and work with many different services or providers:

> 'Yeah, no-one helps people to sort out their driver's licence or sort out their fines or ring [housing services] and sort out their housing. Those sorts of things are really important, I think. And that's what consumers seem to say as well. It's like they don't want to go to four or five different people; they want one person who can address all issues – y'know, one-stop shop.' (#7, drug user organisation)

The success of people in drug treatment (specifically drug substitution therapy) was linked by providers to the success of dealing with complex vulnerabilities in service users' lives:

> '…if people are having family issues, relationship issues, financial issues, court issues, things like that, their anxiety levels – you can discuss it with then, you can talk to them, you can work with them but, until those factors are resolved, they're still going to maintain it [problematic drug use].' (#2, drug and alcohol service)

Another perspective raised by service provider participants was the difficulty of convincing others of varying notions of 'success' in treatment, particularly the difficulty in recognising positive changes in consumers' life circumstances:

> 'But I mean, people complain that they can't send… that GPs won't take patients back and the reason is that there's no education of GPs and GPs don't learn from us, by getting letters and patients back saying, "This is the ratbag

difficult junkie from Lithgow, he's been in Sydney for a month and has been in hospital and been put on buprenorphine", (or some drug they've never heard of), and, "Now look at him; he's upstanding, he's just got a Housing Commission flat and he's got his kid back and is looking for a job in the mines". And the GP will be impressed and say, "Oh, this drug treatment does work". At the moment, a lot of GPs only see our failures and they are rightly very sceptical that drug treatment doesn't really work very well. But in fact drug treatment works as well – better – than anything else doctors do, from diabetes to heart disease to tinea.' (#8, GP)

Housing in particular was seen to be a specific difficulty for people with co-occurring drug and mental health problems in that consumers found it difficult to access services if they were homeless or in unstable housing and that negotiating the housing system (i.e. applying for public housing) required specialised knowledge and perseverance:

'But housing's a much more complicated matter and so yes, people do that – everyone does it – but it's not our area of expertise. You really need access to the Department of Housing personally and there are people who are doing that all the time to keep up with things – it's a full time job for someone to look at housing, all on its own. So again, we'd be more likely to refer people to another service, because it helps them more. Housing gets very complicated because we don't have that knowledge or those links, so most of the housing referrals are crisis accommodation and people do that really well here because there are lots of places here for homeless people that need crisis accommodation. People here know how to do that but, in terms of ongoing housing, that's a bit stickier – because it requires talking to people when they're not intoxicated, for one, or not as intoxicated. There's a lot of stuff to sort out when you're trying to help people.' (#6, drug and alcohol service)

5.5.3   Workforce training and development

Overall, participants described minimal on-the-job training for staff of both drug treatment and mental health services. Training was typically described as occurring periodically (a number of times a year) for short periods (of a day or less). Participants suggested that their own training in dealing with co-occurring drug and mental health issues was limited:

'I would consider myself much more skilled and competent at being able to treat any kind of drug issue, be that drug dependence or whatever, and less skilled at starting someone from scratch on either an antidepressant or an antipsychotic, especially if they haven't been seen by a psychiatrist. That is coming from a degree of concern that the last thing I want to do is complicate the problem.' (#1, drug and alcohol service)

Participants noted the lack of mental health and drug and alcohol training in tertiary courses across medical, health and allied health courses. In addition, the separation of training by the professional medical bodies was seen as problematic:

'The other I think is just from the worker's point of view. Two things – one: there being in-built in the system more overlap and communication and interaction

between D&A and mental health so that it's not so much "never the twain shall meet", that we do… you know, part of our own identity becomes, "If I'm a doctor with my medal, I will quite regularly treat both your D&A issues as well as your mental health issues and that's part of my core business" as opposed to "I'm really a D&A person and therefore I will send you off here"; I think there has to be more of an acceptance of our need to get both specialty training under our belt and broader support in training.' (#1, drug and alcohol service)

'There's too many specialist batsmen and bowlers and not enough all-rounders – is the analogy. We've had this group of clinicians over there and they're the counsellors. You've got this other group of clinicians over here and they're the dosing nurses. Do you know what I mean? Out in the bush, in the scrub here, we've got to be everything; we can't afford that. But unfortunately the direction of education for people working in pharmacotherapy has sort of followed that path link. So unless we get a simpler, holistic approach – and I mean it's well and good if you can have clinical psychologists doing all this sort of work but you just cannot attract them into a lot of centres.' (#2, drug and alcohol service)

5.5.4 Lack of resources, lack of beds and waiting lists as barriers to treatment

A lack of resources was a commonly raised barrier to effective treatment for people with co-occurring mental health and drug issues, particularly the restricted access to mental health services for consumers from the drug and alcohol sector:

'If we actually had a mental health service that we could refer people to – that would make an unbelievable difference. Like that was actually able to function as a mental health service, if you could actually ring them up and be told to bring Sue up now or this afternoon for assessment and knowing that, if we did that, if the person is admitted to mental assistance, that they'd be allocated a case manager who would start working with them. That happens in other areas but it doesn't happen here. That would make a huge difference.' (#6, drug and alcohol service)

One drug treatment service had set up a part-time psychiatric registrar position and noted the significant impact not only in direct service provision to their client group but also on staff training and linkages between drug and mental health services.

5.5.5 Entry criteria for drug treatment as barriers to treatment

Some participants noted that entry criteria for drug treatment programs (specifically for detoxification and rehabilitation programs) were overly restrictive and especially difficult to meet for consumers with co-occurring mental health and drug issues. Rather than trying to match service users with the most appropriate treatments, these restrictive entry criteria were seen as a way for services to reduce the number of cases they had to deal with or to 'cherry-pick' the most motivated consumers:

'…they'll do things like saying motivated people are those people who can prove to us that they're going to go to rehab afterward and also start

off some kind of plan about how they're going to stay clean and show that they've thought it through. And that shows that they're motivated. And if they can't actually do that in an assessment, then we'll say they're not suitable for the program. So I mean that discriminates against people that aren't articulate and discriminates against non-English speaking people – like a lot! It discriminates against people who are just really drug-fucked at the time of interview. I've never seen any research anywhere that proves that people who can start off [with] goal-setting ideas [whether] that actually relates to how well they're going to do in treatment anyway, so I don't know what they're saying. It doesn't make much sense but that's just a couple – every single one I've been to has something about how they do it and it actually doesn't make any sense. It's just their way of dealing with these numbers of people that they can't handle so they go off on a tangent like that. …[it] discriminates against so many people. Like it's obviously favouring white educated people and they're more likely, in whatever state they're in, to be able to get those ideas together because that's the way they've been brought up. It's not related to how well they can do, it's just related to their background. So it's just weird. …So that very process kind of self-weeds out anyone who's not organised and is desperate because they won't manage this series of things to do. And those programs would say, "Well, that's OK because that way we will only get people who are very motivated". Again, it's their way of seeking motivation.' (#6, drug and alcohol service)

5.5.6   Symptoms of depression and anxiety as barriers to treatment

The symptoms of depression and anxiety were noted as barriers to consumers engaging with treatment services. Although this was mentioned by some service provider participants, it was not a strong theme in the interviews with them, although it was recognised that symptoms could pose significant barriers for those service users wishing to access drug treatment:

> '…depression kind of makes people unmotivated and makes it hard for them to do stuff so it makes it hard for them to access anything.' (#6, drug and alcohol service)

> 'Well, I think in terms of people who need motivation, when they are depressed, that may be a barrier to seeking treatment – the same with anxiety, the sort of anxiety they have may as well not be conducive to coming into the clinic or coming in public transport of whatever. So you would think that that could cause extra difficulty for those clients.' (#4, drug and alcohol service)

5.5.7   Medication for mental health problems

Some service provider participants expressed reluctance to initiate medication for mental health problems to avoid adding problems with 'polypharmacy' (using multiple licit and illicit drugs) among service users. Service providers were also concerned that prescription medications might adversely interact with illicit drugs if consumers used them or have a negative impact on the severity of hepatitis C symptoms for those who were infected with the virus:

'…there's a real reluctance to be seen to contribute to any degree of polypharmacy, even if they're not on any other prescription medication. The sense of, "Heavens! This person is putting so many substances into their body, I don't want to complicate the issue by starting them on an antidepressant, for example, especially if I don't necessarily know what they might do with it". So there's a sort of reluctance, I think, to add to any of the polypharmacy that they might have a sense is going on, as opposed to, "Well, actually, that might be causing some of it, might have started some of the drug use in the first place and maybe we can deal with the two things at the same time"... And I think sometimes too, if they're just seeing a general practitioner who isn't necessarily really au fait with all the different drugs and what they might do or not do in a particular setting; if somebody is also using lots of other illicit drugs, there's a potentially complicated problem. Obviously there's a huge prevalence of hepatitis C - sometimes people are concerned that, "Oh, this might worsen my function tests or stuff" and they might not necessarily feel really supported and skilled in terms of what's the best option, what's safe and what is definitely not going to worsen the problem, what would be the best option in terms of starting them on some kind of medication. It's much easier to say, "Why don't we try and sort out your drug use and then see what your mood's like after that?".' (#1, drug and alcohol service)

'And I think often, when they talk about some of their symptoms or their feelings, it's seen as drug-seeking behaviour, which completely invalidates their experience. You know, particularly if people are on pharmacotherapies as well, people are really reluctant to prescribe… or even, with prescribing, referring them to a more appropriate service maybe for counselling or support or whatever, it's just really ignored.' (#7, drug user organisation)

Benzodiazepine prescription for management of anxiety in people with drug dependence was described as problematic by a number of service providers. Some participants said they were reluctant to prescribe benzodiazepines for anxiety management because of the association of this drug class with misuse and diversion for street sale. Other participants suggested benzodiazepine prescription continued to occur because of a limited range of therapeutic alternatives for anxiety.

'I don't think anyone really believes… that includes users, that benzos are really a solution for anxiety. And I think often that doctors that prescribe them are often doing it because they don't know what else to do. Um in my sense, sometimes doctors prescribe them against their better judgment, even if they know the person in their room is… or has been drug dependent. They give it to them because it's the least worst option they can think of.' (#18, drug user organisation)

Chapter 6:
Key informant workshop: description and outcomes

A key informant workshop was held in Sydney, 1 February 2006. Its purpose was to:

- bring together and consult with people who have contributed
  to the study and those who have expertise in the areas of drug
  treatment, mental health and complex vulnerabilities

- share preliminary findings from the service user and service provider interviews

- identify recommendations that may improve the match between
  treatment services and support systems and the needs of illicit drug users
  with mental health problems or other complex vulnerabilities.

The 30 workshop participants included service user representatives, service providers, members of the project Expert Reference Network, the Australian Department of Health and Ageing and project team members (see Appendix G). The workshop was facilitated by Meriel Schultz of LMS Consulting.

6.1   Session 1

The morning session considered the preliminary findings of the service user and service provider interviews. Lance Schultz of LMS Consulting gave a brief overview of the study and its relationship to the earlier *Barriers and Incentives to Treatment* study (Treloar et al., 2004). Dr Martin Holt presented select findings of the service user interviews, and Dr Carla Treloar provided a summary of the service provider interviews conducted by that point in the study.

Annie Madden, Executive Office of AIVL, presented a fictional case study for discussion. The case study concerned a drug user who had sought treatment several times for heroin dependence, and who had been assessed by her case manager as being depressed. The case was discussed in groups from metropolitan and non-metropolitan perspectives, i.e. how should treatment proceed if the service user were living in metropolitan or regional Australia.

Participants were asked to use the case study as starting point for discussion. Specifically, they were asked to consider:

- the key challenges that face service providers and service users when
  dealing with co-occurring drug and mental health problems

- how the use of clinical terminology (e.g. comorbidity/dual diagnosis) impacts
  on communication between service users, providers and policymakers

- what constitutes effective service delivery for service users

- barriers to treatment

- workforce issues that impact on effective service delivery
  and quality outcomes for service users

- the role of service users, peers and family in developing
  effective services and support mechanisms

- 'ideal' models of service provision and support systems.

6.1.1 Key challenges

Key informants suggested that there was a need to rethink the way services were conceived and delivered. Participants referred to narrow conceptions of 'service' and the inflexibility of service provision. This was reflected in funding arrangements for the treatment of users with mental health and complex vulnerabilities, and a lack of clarity in the definition of roles and responsibilities of health and other service providers, GPs, counsellors, case managers and drug user organisations.

Service provider participants reported feeling frustrated in dealing with high prevalence disorders, such as anxiety and depression, as it was perceived that there were more avenues for referral for those who presented with psychotic disorders.

Participants noted that the system as it is currently operating is not well serving people with co-occurring drug and mental health problems and could result in users with high prevalence conditions and complex vulnerabilities being denied assistance for their basic needs.

6.1.2 Use of clinical terminology

Key informants noted that service user participants did not understand the clinical terms such as 'comorbidity' and 'dual diagnosis'. Key informants considered whether this lack of understanding could have a bearing on treatment outcomes. It was agreed that service providers tended not to use clinical language with service users, as this could be seen as a barrier to client understanding, but there was debate about whether the lack of use of clinical terminology with service users could further hinder treatment outcomes.

6.1.3 Effective system/service delivery

Participants spoke of the need for improvements in coordinated care to ease the access of service users to relevant services. This could take a number of forms, such as: the integration of services; one-stop shops; co-location of services; consultation between AOD, mental health and other services; visiting and staff exchanges between services. However, consideration needed to be given to the different agendas of the agencies involved, e.g. AOD, mental health, police, departments of community services and family services. In some instances the integration of services may not be appropriate or feasible, but streamlined referral processes and communication between services could be improved.

Effective case management was noted as critically important for effective service delivery. However, it was noted that there is considerable variation in the way that 'case management' is understood and the extent to which quality case management practices are implemented. The distinction and linkages between high coordination of care, case management and shared care need further clarification with service providers, especially how these approaches to care are defined and implemented, and how service providers envisage their roles and responsibilities within these service models.

Some key informant participants spoke of the need for the development of appropriate diagnostic tools for the identification of co-occurring disorders, better communication in diagnosis between drug treatment, mental health services and GPs, and a better system of referral from drug and alcohol and mental health treatment services to services that address other aspects of 'complex vulnerabilities' such as transport, housing and child care.

6.1.4 Barriers to drug treatment

In addition to the issues raised under other headings in this section, participants referred to other barriers to treatment relating to:

- structural issues, such as limited resources, the number of available treatment places, the frequent reorganisation (and relocation) of treatment services and the small number of counsellors in AOD services

- organisational barriers, such as restrictions on the way that methadone management programs can be implemented, and the 'rush to prescribe antidepressants by some health professionals

- personal circumstances, including transportation costs to attend treatment and service users' difficulties in meeting the cost of methadone dispensed by pharmacies, and consequent pharmacy debt.

6.1.5 Workforce issues

Workforce development issues were identified as a particular priority in the improvement of services for people with comorbidity and complex vulnerabilities. There was a perception that the skills of the AOD and mental health sectors needed to be upgraded to meet the challenges of comorbidity and complex vulnerabilities, particularly in relation to delivering coordinated care.

The roles and responsibilities and skills base of case workers and counsellors needed clarification. This may require some re-evaluation of current methods of service provision, e.g. the development of national protocols for case management and care planning for service users with complex vulnerabilities, and the investigation of the training provided and skills required to enable the application of effective case management and care plans for this group of service users with complex vulnerabilities. These elements were described by workshop participants as requirements of ongoing training and clinical education for health professionals (e.g. with GPs, mental health and drug and alcohol service providers and community pharmacists) who are in contact with service users in the target group.

It was noted that there were problems in recruiting and retaining health professionals in small towns or regional areas, and in the provision of support to allow effective networking across the range of health professionals, who provide services to people with drug and mental health comorbidities.

6.1.6 Consumer participation in treatment

Participants noted the lack of involvement of service users in treatment plans, leading to a mismatch between provider and service user aims, concerns and treatment provision. For example, it was noted that in the service user interviews, many service users reported that they did not understand the possible effects of the medications they had been prescribed. Key informants from drug user organisations noted that it was not uncommon for users to bring pills to their local drug user organisation and ask for the effects of prescribed medication to be explained, rather than going back to their prescribers.

The workshop participants agreed that there were clear opportunities for peer support in improving treatment outcomes for people with both drug and mental health problems.

Drug user organisations could make an invaluable contribution in supported referrals, advocating for service users and ensuring service users got the assistance they needed, although treatment services would need to acknowledge the role of peers.

6.1.7 Ideal models of service provision and support systems

Workshop participants commented that few of the service user or service provider study participants appeared to have experienced models of best practice. The view was expressed that, as the barriers to drug treatment for service users were now generally well known, it was more important to focus on what would happen if the system worked well. Both integrated service models and service models demonstrating low threshold, easy access pathways of care for service users presenting with complex mental health, substance use and other needs, could be introduced/strengthened in Australia, building on the models available (e.g. Kirketon Road Centre, Sydney) and taking into consideration overseas experience.

6.1.8 Differences between metropolitan and non-metropolitan services

Participants noted that drug treatment for service users in non-metropolitan areas was constrained by available resource levels, limited treatment choices, and the heightened stigma attached to illicit drug use, mental health, and hepatitis C in small communities. It was suggested that while service providers in regional areas may be less specialised in some aspects of AOD and mental health treatment, they often had a broad, well-balanced experience in dealing with the range of issues facing service users with comorbidity. Regional service providers could also be highly motivated, and out of necessity develop a range of local contacts and knowledge of what was available that could help service users best access treatment. It was suggested that regional providers could display a willingness to go beyond their established roles in order to help clients. However, it was suggested that professional support for GPs working in regional areas and with people with comorbidity was poor.

6.2 Session 2

Participants were invited to continue the morning discussion in small groups and to 'brainstorm' possible areas for inclusion in the study's policy and program recommendations. The following points were discussed and considered important for change:

- adopting an holistic approach, focused on the individual, his or her complex needs and the environment in which substance use, mental health and other vulnerabilities arise

- adopting a strengths-based approach, recognising the capacities of service users and focusing on teamwork and networking within service provision

- adopting a settings approach, locating primary access points near service users and connecting people in their communities with the nearest available services

- identifying 'levers for change' – the simplest and most efficient ways to improve treatment provision

- adopting a 'can do' approach, shifting the focus from 'barriers' to treatment in order to make things happen.

In keeping with the original *Barriers and Incentives to Treatment for Illicit Drug Users* study (Treloar et al., 2004), the facilitator suggested the following key result areas as a framework for developing policy and program recommendations:

• strategic directions

• quality practice

• consumer involvement

• workforce development

• continued research

• other.

6.2.1 Strategic directions

Participants advocated for service planning, delivery and review processes with a much stronger focus on individual wellbeing within which:

• Health professional and allied workers' communication skills would be enhanced, improving the capacity to respond to both physical needs and the broader wellbeing of service users, i.e. within the public health model that considers the person, the mix of health issues presenting and the environment/context in which the health issues occur.

• Consideration would be given to appointment of 'lead agencies' responsible for coordination of care other than specialised drug and alcohol or mental health services (including agencies outside health). Criteria for nomination as a lead agency would be based on demonstrated capacity to coordinate services that meet the physical and psychosocial needs of the service user and inclusion of an appropriate mix of accessible health care services as part of an effective shared care model.

• Referral options are broadened, enabling health professionals to be funded and supported to include counselling and other, e.g. social, legal and financial referrals, as part of their case management processes. A start has been made on this kind of approach through programs such as the Australian Government's *Better Outcomes in Mental Health Care Initiative* for GPs and the *Lifescripts* Program, introduced in the primary health care sector to address a number of key risk factors related to chronic disease.

• State, territory and federal governments would seek nominations from and fund networks of services that better integrate mental health and AOD service provision with general health services and broader systems, such as welfare and criminal justice. Such funding should allow for flexible and appropriate models for local settings.

• The Australian Government Department of Health and Ageing monitor and disseminate examples of best practice in holistic care of service users with comorbid anxiety and depression disorders.

• State and territory funding agreements would include benchmarks for both mental health and drug treatment outcomes such as evidence of inter-service relationship building, consumer involvement in service planning and treatment delivery, and ethical work practices.

6.2.2 Quality practice

Participants nominated the following core criteria for both drug and mental health service best practice guidelines. In meeting the needs of clients appropriately at all life stages, services should:

- provide well-coordinated, shared care and continuity of care
- use culturally appropriate methods
- provide ease of access and equity in service provision
- be closely monitored and evaluated to ensure that guidelines (including core criteria) are put into practice.

The ideal model where co-occurring drug and mental health treatment was needed, was seen as:

- de-institutionalised and including coordinated and long-term care
- promoting knowledge sharing and service partnerships
- providing access to a range of available services that involve and support the user
- promoting regular communication between service providers (with service user consent)
- based on a 'strengths based' approach that works to build service user knowledge, skills and decision making in treatment.

Regular and simple processes for review and follow up should be the focal point of an effective system.

6.2.3 Consumer participation

Workshop participants considered that, as part of meeting quality assurance and guidelines for funding, services should include supported and satisfactory levels of consumer participation. Consumer participation should be implemented through identifiable protocols and processes that encourage involvement and consultation with service users at all levels and stages of treatment, and as part of ongoing service planning, delivery and review.

Key informants considered that while a number of health services do have appropriate mechanisms in place, considerable cultural change among some drug and mental health services would be needed to change the attitudes of service providers towards service users and consumer participation.

6.2.4 Workforce development

Participants noted that improving community access to quality primary mental health and AOD health services would require a wide range of workforce training and development of various kinds and at various levels. These included:

- additional education for GPs in management of service users with both mental health and drug and alcohol issues
- improved opportunities for skills development in relation to mental health and substance use management, including recognition, assessment procedures, and

evidence based interventions, referral processes and review mechanisms. This should occur at undergraduate level as well as on going education and be *common* across a range of health disciplines including for health professionals in medicine, psychology, drug treatment, social work, pharmacy and occupational therapy

- experiential learning through combined training, placements, exchanges between mental health and AOD services and other services, especially with the primary health care sector
- training for health professionals to understand complex vulnerabilities impacting on service users' wellbeing, e.g. the criminal justice system, policing, family and community services, housing, welfare
- training in case management and in the implementation of effective models of shared care.

Participants also considered that state, territory and federal governments must increase the levels of funding currently allocated to knowledge and skills development among service providers for the following issues:

- working and communicating with service users with complex needs
- identifying best practice in the implementation and coordination of long-term, shared care
- using multi-agency approaches in community settings.

6.2.5   Continued research

Recognising that considerable research has already been undertaken to identify barriers to treatment and support for people with drug and mental health issues, participants suggested two main types of research that should be funded by state, territory and federal governments:

- identifying cost-effective models of service delivery for the treatment of illicit drug users with comorbidity and complex vulnerabilities in community settings
- reviewing, clarifying and defining best practice in 'case management' for people with co-occurring drug and mental health problems.

Chapter 7:
Recommendations

Recommendations are based on the findings of the study and a combination of input from service users and service providers, key informants, the expert reference network and the project consortium members. In particular, recommendations reflect service user perspectives, supported by information from service providers and key informants.

Overall, a vision emerges that signals the continued need for a national, conjoint illicit drug and mental health treatment system to be developed with the following principles:

- holistic treatment and continuity of care should be the core business of drug treatment services, as it is for other parts of the health system

- integrate treatment with the public health model using a range of strategies

- recognition that the treatment needs of people who use illicit drugs and who are living with a high prevalence mental health problem, such as anxiety and depression, are an important area of unmet need

- recognition that people who use illicit drugs, as service users, have the same rights as any other consumer within the Australian health system

- instigating low threshold, easy access for service users with complex needs

- integrating and co-locating a range of treatment options within services

- adequately resourcing and training staff in co-occurring drug and mental health problems

- encouraging and supporting consumer advocacy and the active participation of consumers within treatment services

- recognising the roles and support needs of families and carers

- recognising that in treatment settings people who are seeking help for illicit drug use more often than not present with high prevalence mental health disorders and complex vulnerabilities (i.e. these are 'part of the territory').

Such a system would bring together, for the benefit of the service user, the sensible and practical elements of the currently separated drug and mental health systems, allowing for a mix of sequential, parallel and integrated approaches to treatment, while continuing to recognise the differences and specialist elements contained in each of these sectors.

The recommendations (and proposed actions) that follow draw on the above principles. They are consistent with and complement other schemes funded under the National Comorbidity Initiative. The accompanying suggested actions are designed to assist service providers and policymakers in attracting people who use illicit drugs with mental health and other problems into treatment, and to make the experience of treatment more supportive and effective for these health consumers.

Where relevant and appropriate, reference is made in the comment sections to the recently released report by the Senate Select Committee on Mental Health, *A national approach to mental health* (2006).

In accordance with the directions suggested by key informants, recommendations seek to identify levers for systems and service change and to reflect a forward looking,

strengths-based approach that supports positive outcomes in relation to the health, mental health and general wellbeing of people who use illicit drugs.

The recommendations are grouped according to the framework used for the earlier study of *Barriers and Incentives to Treatment for Illicit Drug Users* (Treloar et al., 2004). Key informants in the current study re-endorsed this framework, agreeing that recommendations should be grouped in the following areas:

- strategic directions
- quality practice
- consumer involvement
- workforce development
- continued research.

7.1   Strategic directions

Recommendation 1 – Holistic treatment
As a matter of urgency, that all governments recognise the shortcomings of the health system in meeting the needs of service users with complex needs that include substance use and high prevalence mental health problems, and make the reform of relevant policies, service planning, delivery, monitoring and review a priority in health system reform.

Suggested Action
That governments work together with the non-government sector and other key stakeholders to implement formal and high-level partnerships for service planning between policy makers, mental health services and alcohol and other drug services to ensure a holistic approach including linkages with other relevant services such as housing and employment.

Comment
The recommendation addresses the widely acknowledged problem of service users 'falling through the cracks', seeks to promote a 'no wrong door' policy and reflects recommendations 66 & 68 in the Senate Select Committee on Mental Health report (2006).

Recommendation 2 – Prevention and early intervention
That federal, state and territory governments recognise the negative impacts of social exclusion and the importance of giving attention to the full range of social determinants of health.

Suggested Action
Governments work with service providers to actively develop and fund collaborative action between relevant stakeholders to enhance prevention and early intervention measures for people with substance use problems, co-existing mental health problems and other complex vulnerabilities.

Comment

Service user accounts suggest early childhood and family experiences, particularly experiences of poverty, poor housing and other social disadvantage, are strongly associated with initiation into illicit drug use and the development of mental health problems.

Recommendation 3 – Funding of service provision

That federal, state and territory governments coordinate state and federal policy directions and associated funding on drug and mental health issues, prioritising funding for services that better integrate mental health and AOD service provision together with general health services and broader systems, such as welfare and criminal justice. Such funding should allow for flexible and appropriate models for urban and regional settings.

State and territory funding agreements should include both health and wellbeing outcomes (e.g. relationship building, consumer involvement, ethical work practices) and regular reporting against agreed health and wellbeing indicators.

Comment

Key informants strongly supported funding arrangements that better integrate service provision in relation to AOD issues, mental health treatment and wellbeing outcomes.

Recommendation 4 – Community education

That the Australian Government continue, as a long term strategy, to support national public education campaigns related to the joint topics of illicit drugs and mental health issues, paying particular attention to high prevalence conditions such as anxiety and depression.

Suggested Actions

Re-align education campaigns to address the stigma of illicit drug use. Seek to change public perceptions of illicit drug use and mental health problems so that these issues are recognised as legitimate and integral parts of health care in Australia.

Comment

The study found that the additional stigma of a mental health diagnosis was a continuing barrier to mental health treatment for service user participants.

7.2   Quality care and practice

Recommendation 5 – Rights of service users

All governments recognise and actively support health system reform that brings the inclusion of service users with drug dependence and mental health problems in line with the accepted conditions for service users in other parts of the health system.

Suggested Actions

• Align National Drug Strategy and National Mental Health Strategy priorities to guarantee access for people with co-occurring drug and mental health problems to services that provide a non-threatening and

friendly environment (recognising that high prevalence conditions such as anxiety and depression can impact on the ability and motivation to comply with treatment regimes and visits to multiple service providers).

• Require service plans and reporting to indicate the level of, and mechanisms for, active participation by service users in determining their treatment.

• Develop a consistent approach between future National Strategies for specific measurable health outcomes for service users with mental health and drug dependence problems. Ensure these outcomes are monitored and reported annually at service, state/territory and national levels.

• State and territory health ministers take action in relation to rural and remote drug treatment and mental health service provision as outlined in recommendations 82 to 88 in the Senate Select Committee on Mental Health report (2006).

Comment
Service user participants in the study reported favourably on services that were low threshold, friendly, free, and interconnected. These kinds of service provide easy access to treatment and facilitate continuity of care, as in other parts of the health system.

Key informants proposed that state and territory funding agreements include health and wellbeing outcomes for both drug and mental health treatment sectors, e.g. establishing relationships between services, promoting consumer participation in treatment, implementing and monitoring ethical work practices.

Service users in rural and remote areas are recognised in this study and by the Senate Select Committee on Mental Health (2006) as lacking access to appropriate community resources and information, including community-based mental health centres. The delivery of services in rural and remote areas is also hampered by a lack of choice in drug treatment options, inflexibility in the allocation of Medicare provider numbers for mental health professionals, and a lack of support and training for the existing workforce, including drug treatment staff, GPs and mental health professionals.

7.3   Consumer involvement and advocacy

Recommendation 6 – Consumer education
The Australian Government recognise the importance of up-to-date, accurate consumer information and education for people with illicit drug and mental health problems and other complex vulnerabilities.

Suggested Action
The Australian Government Department of Health and Ageing fund the production, distribution and implementation of national educational resources and programs developed by users to increase service user literacy about mental health, drug use and treatment issues (including medication). Resources should be distributed through drug user and mental health organisation networks, and resources should be available in or through drug treatment settings. Educational programs can be delivered by drug

user organisations or within treatment settings with peer oversight. Dissemination of resources should be accompanied by workshops in each of states and territories to raise awareness among consumers and service providers.

Comment
The service user arm of the study found that, in general, users:

• did not understand the clinical terms 'comorbidity' and 'dual diagnosis'

• were more able to understand and talk about experiences of drug use compared with mental health

• had a poor understanding of anxiety and depression, including their causes, symptoms and management

• did not understand why they had been prescribed particular medications for mental health problems, what the effects of these drugs could be, or whether they could explore alternative treatment options

• were more likely to understand the relationships between drug use and mental health if they had participated in peer-led education or received drug user organisation literature on comorbidity.

A poor understanding of the relationship between mental health and drug use among users is likely to be a barrier to effective drug and mental health treatment.

7.4   Workforce development

Recommendation 7 – Workforce incentives
That the Australian Government recognise the need to provide support to the drug and mental health workforce through:

• increases in health professional positions, especially in the primary health care and community health sectors

• provision of incentive payment schemes that enable adaptation of services to better integrate care and/or allow for stronger referral pathways for service users with complex needs.

Suggested Action
The Australian Government reform current incentive schemes (e.g. the *Better Outcomes in Mental Health Care Initiative*) to include Medicare mental health schedule fees and rebates for *combinations* of employed or contracted staff – including psychiatrists, psychologists, general practitioners and practice nurses. New positions in these areas should be supported and encouraged by funding arrangements.

Comment
Study findings reiterate the need for drug treatment services to either incorporate mental health professionals within their services, or have easy access to mental health services in external agencies. Service providers said that even well established services struggled to institute these kinds of arrangements without adequate funding.

Recommendation 8 – Training and education

That all governments work together (in line with Council of Australian Governments agreements) to identify, streamline and fund ongoing education and training for health professionals engaged in work within the drug treatment and mental health sectors.

Suggested Actions

- That the Australian Government Department of Health and Ageing fund the production of a training module for mental health and drug treatment frontline workers to increase recognition that people with illicit drug problems will often experience high prevalence mental health conditions and complex vulnerabilities and that these should be incorporated into standard patterns of care.

- That state and territory governments facilitate within their service agencies:

    - management and other staff training on the development and implementation of transparent service protocols and the publication of a clear treatment philosophy

    - the use of joint memoranda of understanding between identified service partners

    - integrated training for drug treatment and mental health staff, including assessment techniques, evidence based interventions, referral systems, coordination of care and review mechanisms

    - rotation of staff across agencies in the different service sectors to promote knowledge transfer and skills development

    - training in case management and development of integrated care plans

    - identification of dedicated liaison positions within services to enable better feedback mechanisms and continuity of care across services.

Comment

Participants at the key informant workshop noted that community access to quality drug treatment and mental health care would require a range of workforce training and development. They placed considerable emphasis on integrated training, particularly in case management.

The Senate Select Committee on Mental Health (2006) recommended the need to upgrade health professionals' skills for assessment, referral and treatment of co-occurring drug and mental health conditions.

7.5   Continued research

Recommendation 9 – Data collection

That the Australian Government Department of Health and Ageing recognise the need for research that focuses on the combinations of drug and high prevalence mental health disorders and the establishment of national indicators detailing the treatment population, treatments provided and treatment pathways.

Suggested Action

That the Australian Government commission the design and collection of comprehensive data on service provision for service users presenting with mental health and substance

Barriers and Incentives to Treatment for Illicit Drug Users with Mental Health Comorbidities and Complex Vulnerabilities

use problems, paying particular attention to those presenting with high prevalence conditions such as anxiety and depression.

Comment

As part of the National Comorbidity Initiative, the Australian Institute of Health and Welfare was contracted to establish and report on the current state of data collections relating to people with co-occurring drug and mental health problems in Australia. The above recommendation focuses on the co-occurrence of anxiety and depression with illicit drug problems, and includes treatment for anxiety and depression provided by alcohol and other drug services, where available.

Recommendation 10 – Models of service delivery

The Australian Government Department of Health and Ageing identify effective models of service delivery for service users with complex needs including substance use and mental health problems, recognising that fully integrated service provision may not be viable in all locations in Australia.

Suggested Action

The Australian Government commission studies to evaluate the effectiveness of:

- integrated service models

- service delivery models demonstrating strong pathways of care between separate drug treatment, mental health and other support services.

Effectiveness of these different (integrated and non-integrated) models should be assessed in terms of service user outcomes (including consumer satisfaction).

Comment

The literature review underpinning this study found that:

- Treatment services tend to be assessed by measures that reflect clinical priorities (e.g. cessation of drug use), and not necessarily those of consumers.

- Reviews and evaluations of 'best practice' have tended of focus on the experiences and needs of health professionals.

From the service user arm of the study, participants tended to favour integrated approaches that were low threshold, emphasised trust and understanding, were harm reduction based, and provided avenues to social support. However, service providers (particularly those from rural and regional areas) noted the difficulty in instigating integrated care in resource-poor settings. Robust inter-service agreements are therefore needed to make best use of local resources.

Chapter 8:
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Appendix A –
Expert Reference Network members

Antoinette Aloi, Centre for Drug & Alcohol, NSW Health

Nicky Bath, Treatments Program and Policy Officer, Australian Injecting and Illicit Drug Users League

Lynne Magor-Blatch, Director, Client Services, Karralika, A.C.T.

Donna Bull, Chief Executive Officer, Alcohol and the other Drugs Council of Australia

Dr Lucy Burns, Lecturer, National Drug and Alcohol Research Centre, University of New South Wales

Barbara Hocking, Executive Director, SANE Australia

Professor David Kavanagh, Department of Psychiatry, University of Queensland

Dr Rod McQueen, Director, Lyndon Withdrawal Unit, Orange, NSW

Elizabeth Morgan, Chair, Network of Australian Consumer Advisory Groups

Dr Alan Quigley, Director, Next Step Alcohol and Drug Services, Perth, Western Australia

Dr Sandra Sunjic, Service Manager, NSW Drug Court Program

Noel Taloni, Director, Illicit Drugs Section (subsequently the Illicit Drugs – Emerging Trends & Comorbidity Section), Australian Government Department of Health and Ageing [Replaced by Klaus Klauke in 2005 and Cath Phillips in 2006]

Tony Trimingham, Chief Executive Officer, Family Drug Support

Dr Tori Wade, Primary Mental Health Care Australian Resource Centre, Flinders University [2004-2005]

Kerry Webber, Director, Mental Health Strategies Section, Australian Government Department of Health and Ageing [Replaced by Maria Jolly in 2006]

Professor Ian Webster, Emeritus Professor, School of Public Health and Community Medicine, University of New South Wales

Michelle Wilson, Director, Youth Bureau, Australian Government Department of Family and Community Services [Replaced by Grant Witcombe in 2006]

Scott Wilson, Director, Aboriginal Drg & Alcohol Council, South Australia

Appendix B –
Service user interview schedule

Preliminaries:
Confirm English language comprehension, age, understanding of project and consent to participate.

Collect/confirm background details i.e. pseudonym, drug type(s) related to treatment, whether in treatment, treatment history or considering treatment, current mental health diagnosis/problem or recent history of eligible condition

Questions/topics for discussion:

1.   Drug treatment experiences
Please tell me about your recent experiences of drug treatment.

What types of treatment have you accessed or tried to access e.g. pharmacotherapy, detox, counselling, rehab? Did you get what you wanted from treatment? Have you had problems accessing or staying in treatment?

2.   Mental health treatment
Have you sought or received separate treatment for your mental health problem? From where? Was it easy to access treatment? What did the treatment entail? Was it effective or useful for you?

3.   Mental health problems
Please tell me about your most recent mental health problem(s). How did they affect you? How did you manage? Does the problem affect your family and friends and your ability to access drug treatment?

4.   Understanding of the term comorbidity/dual diagnosis
Do the terms comorbidity and dual diagnosis mean anything to you? If so, what? Have they been used to describe you or someone you know?

5.   Managing comorbidity
Do you do anything to manage your drug use and mental health problem, aside from accessing formal treatment services? i.e. self-medication

6.   Accessing services as a client with comorbidity
Have you had problems accessing services as a person with drug use and mental health problems? How were you treated the last time you accessed services? If you have had difficulties, how did this impact on your life?

7.   Relationship between drug and mental health services
If you have accessed both drug and mental health services, how would you say they compare? Is one service prioritised over the other? If you received treatment from both

services at the same time, did that work well for you? Were there competing demands i.e. being drug-free to access MH services?

8. *Specialist services*
Have you accessed services designed to deal with both drug use and mental health issues? What do you think of them?

9. *Barriers to treatment*
If you have experienced problems in accessing or remaining in treatment programs, what do you think caused these problems? Discuss personal, interpersonal, organisational and societal barriers. Prompt for discussion of criminal justice issues, if appropriate.

10. *Incentives to treatment*
What would make it easier for you to access or remain in drug treatment and/or mental health services? What changes would you like to be made to existing services?

11. *Consultation*
During your last experience of drug treatment, were you consulted by your doctor or specialist about what course of treatment would be best for you? i.e. did you get input into your treatment plan?

12. *Attitude of staff*
What was the attitude of treatment staff in general to you? Did they respect your confidentiality i.e. keeping your details private from other clients, staff and services?

13. *Peer support*
Have you received or participated in peer support/mentoring programs? How did you find them? Would they be useful in the future?

14. *Complex vulnerabilities*
Have you sought support for other issues, such as: employment, welfare, housing, hepatitis C, relationship counselling? What sort of support did you received and how helpful was it?

15. *Future drug treatment*
If you are looking to access drug treatments in the future, what would be a good outcome for you? What would be an ideal treatment service for you?

Demographic items to collect/confirm:
- Age
- Sex (Male/Female)
- Country of birth
- Ethnicity
- Any Aboriginal/Torres Strait Islander background
- Highest level of education
- Main source of income
- Current abode

Appendix C –
Checklist for peer recruiters

To help you decide if a person is eligible to participate in this study, the following criteria checklist will need to be worked through. These criteria are designed to be discussed in an informal manner so you can use your own language to discuss each point. We do need you to tick the boxes so we have a record of who is recruited or excluded from the study. Please refer to the peer recruiters' manual for extra guidance.

Participant details		Male	Female	
1.	What is the person's gender?			
2.	Ask the person to choose a pseudonym (a name to protect their identity in the research)	(Write pseudonym here)		

Basic eligibility criteria		Yes	No	Directions
3.	Are you 18 years of age or over?			If **No**, then stop.
	How old are you? (record age)		yrs	
4.	Does the person speak English well enough to participate in an interview?			If **No**, then stop.

Ability to consent, understand, and participate safely		Yes	No	
5.	Do you believe the person can provide informed consent to the project? Please refer to section of peer manual on informed consent.			If **No** to **any** of these, then stop and offer referral contacts.
6.	Do they understand the nature of the project? • talking about their drug use • talking about their mental health • talking about their experience of drug treatments			If **Yes** to **all**, then proceed.
7.	Are they able to concentrate on the discussion and carry on a conversation?			
8.	Do you think the participant and researchers will feel safe if an interview takes place?			
9.	Do you feel confident in referring them to the researchers?			

Illicit drug treatment history		Yes	No	Directions
10.	Have you sought treatment for **illicit** drug use in the last 2 years?			If **No**, then go to 11.
If **Yes**, then for which drugs? (indicate all)	Cannabis			If cannabis **only**, then this person cannot take part in the study (go to 11).
	Stimulants e.g. amphetamines, cocaine, crystal, ecstasy			If **Yes** to either stimulants or opiates, then this person can take part in the study (complete 11 anyway)
	Opioids e.g. heroin, opium, morphine, methadone			
	Other **illicit** drugs (please specify)			
If **Yes**, then what type(s) of treatment did you receive? (indicate all)	Pharmacotherapy e.g. methadone, naltrexone			
	Counselling			
	Detoxification			
	Residential Rehabilitation			
	Other			
11.	Are you considering treatment for **illicit** drug use?			If **No** to 10 and 11, then stop.
If **Yes**, then for which drugs? (indicate all)	Cannabis			If cannabis **only** (in 10 and 11), then this person cannot take part in the study.
	Stimulants e.g. amphetamines, cocaine, crystal, ecstasy			If **Yes** to either stimulants or opiates, then this person can take part in the study (proceed)
	Opioids e.g. heroin, opium, morphine, methadone			
	Other **illicit** drugs (please specify)			
To be eligible, person **must** have either sought treatment or be considering treatment for opioid or stimulant use. Treatment for cannabis use alone is not sufficient.				

Barriers and Incentives to Treatment for Illicit Drug Users with
Mental Health Comorbidities and Complex Vulnerabilities

Mental health history		Yes	No	Directions
12.	Do you have a **current**, diagnosed mental health problem?			
If **Yes**, then what type of mental health problem?	**Mood and affective disorders** (indicate which)			If **Yes**, does current condition impair ability to participate? If not, then person can take part.
	Anxiety			
	Non-psychotic depression			
	Panic disorder			
	Post-traumatic stress disorder (PTSD)			
	Other			
	Other conditions (indicate which)			If **Other conditions** currently present, then this person cannot take part in the study.
	Schizophrenia/psychosis			
	Major depression			
	Personality disorder			
	Dementia			
	Learning disabilities			
	Other			

Mental health history		Yes	No	Directions
13.	Have you sought treatment for a mental health problem in the past 2 years?			
If **Yes**, then what type of mental health problem?	**Mood and affective disorders** (indicate which)			If **Yes** to this category, then participant is eligible.
	Anxiety			
	Non-psychotic depression			
	Panic disorder			
	Post-traumatic stress disorder (PTSD)			
	Other			
	Other conditions (indicate which)			Previous treatment for another condition does not prevent participation.
	Schizophrenia/psychosis			
	Major depression			
	Personality disorder			
	Dementia			
	Learning disabilities			
	Other			
People must have **either** current experience of mood/affective disorders or have sought treatment for mood/affective disorders in past 2 years to be eligible.				
People should **not** be recruited if their current mental health problems are severe enough to affect their ability to participate safely.				
People with current mental health problems other than mood/affective disorders should be declined.				

Barriers and Incentives to Treatment for Illicit Drug Users with
Mental Health Comorbidities and Complex Vulnerabilities

Appendix D –
Example of service user participation information sheet and consent form

The following participant information sheet and consent form was the version approved by the University of New South Wales Human Research Ethics Committee. When used, the form was printed on headed paper with the university's crest and National Centre in HIV Social Research contact details.

Approval No. HREC 04181

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
The experiences of drug treatment clients with comorbidity and complex vulnerabilities

Purpose of study
You are invited to participate in a study of barriers and incentives to drug treatment for illicit drug users with mental health issues and other needs. We hope to learn about users' experiences of drug treatments so that we can identify how these services might be improved. We will also be talking to service providers about similar issues. You were selected as a possible participant in this study because you are aged 18 or over and you have experience of drug use and mental health issues.

Description of study
If you decide to participate, we will interview you about your experience of drug use and mental health issues, and your experience of drug treatment services. Interviews will last up to 1 hour. The interview will be relatively informal and is unlikely to cause distress or discomfort. However, if you find any aspect of the interview distressing or uncomfortable, you have the right to stop and withdraw at any time.

You may benefit from participating in this study if, as a result of the study, drug treatment services in your area are changed to better suit your needs. However, we cannot guarantee that you will receive any benefits from this study.

Recompense
You will receive $20 in expenses for taking part in the study.

Confidentiality and disclosure of information
Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission, except as required by law. If you give us your permission by signing this document, we plan to publish the results in a community report and journal articles. The report will contain recommendations for the improvement of drug treatment services. In any publication, information will be provided in such a way that you cannot be identified.

Consent and right to withdraw

Your decision whether or not to participate will not prejudice your future relations with The University of New South Wales or the National Centre in HIV Social Research. Participating in the study does not affect your right to use drug treatment services. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

Complaints about the conduct of the study may be made to the Ethics Secretariat, University of New South Wales, Sydney, NSW 2052 (phone 02 9385 4234, fax 02 9385 6648, email ethics.sec@unsw.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

If you have any questions, please feel free to ask us. If you have any additional questions later, Dr Carla Treloar (02 9385 6959 or c.treloar@unsw.edu.au) will be happy to answer them.

Please keep this statement for future reference.

THE UNIVERSITY OF NEW SOUTH WALES and NATIONAL
CENTRE IN HIV SOCIAL RESEARCH

REVOCATION OF CONSENT

The experiences of drug treatment clients with comorbidity and complex vulnerabilities

I hereby wish to **WITHDRAW** my consent to participate in the above named study
and understand that such withdrawal **WILL NOT** jeopardise any treatment or my
relationship with The University of New South Wales or National Centre in HIV Social
Research.

_____

Signature   Date

_____

Please PRINT Name

The section for Revocation of Consent should be forwarded to Dr Carla Treloar, National
Centre in HIV Social Research, University of New South Wales, Sydney, NSW 2052.

Complaints about the conduct of the study may be made to the Ethics Secretariat,
University of New South Wales, Sydney, NSW 2052 (phone 02 9385 4234, fax 02
9385 6648, email ethics.sec@unsw.edu.au). Any complaint you make will be treated in
confidence and investigated, and you will be informed of the outcome.

THE UNIVERSITY OF NEW SOUTH WALES and NATIONAL
CENTRE IN HIV SOCIAL RESEARCH

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
The experiences of drug treatment clients with comorbidity and complex vulnerabilities

You are making a decision whether or not to participate. Your signature indicates that, having read the Participant Information Statement, you have decided to take part in the study.

_____   _____
Signature of Research Participant   Signature of Witness

_____   _____
(Please PRINT name)   (Please PRINT name)

_____   _____
Date   Nature of Witness

_____
Signature(s) of Investigator(s)

_____
Please PRINT Name

Appendix E –
Coding framework used for service user interviews

Code number followed by description:

1. Drug use history (e.g. first experiences of illicit drugs, introduction to opiates/stimulants)

2. History/experience of formal drug treatment

3. Self management/treatment of drug use

4. Mental health
    a. own description/explanation of problem
    b. symptoms/effects – depression
    c. symptoms/effects – anxiety
    d. evaluation of treatment/services for
    e. disclosing/discussing drug use in mental health setting
    f. self-management of
    g. antidepressant medication
    h. medication for anxiety
    i. counselling/psych input
    j. impact on family/social relations/work

5. Comorbidity
    a. understanding of term/language
    b. any experience of integrated treatment
    c. explanations of relationship between drug use and mental health (i.e. how one affects the other, common causes, no relationship)
    d. effects of comorbidity on treatment

6. Barriers to drug treatment
    a. access/availability
    b. choice/suitability of treatment
    c. cost
    d. coercion
    e. stigma (e.g. social/societal attitudes)
    f. attitude of staff/service
    g. privacy/confidentiality
    h. mental health problems as barrier to participation
    i. continued drug use
    j. other barriers

7. Incentives to treatment/ideal treatments
    a. accessibility
    b. flexibility
    c. attitude

8. Experience of drug treatment – substitution/pharmacotherapies
   a. accessing/starting program
   b. attitude of staff
   c. peer support
   d. consultation – input into treatment plan
   e. dosing schedules and impact of
   f. impact of regulations (inc. monitoring)
   g. relationship with prescribing doctor
   h. relationship with pharmacy
   i. takeaways (inc. diversion)
   j. disclosing/discussing mental health in AOD setting
   k. access to mental health services
   l. access to other services
   m. what it's like for me (personal impact)

9. Experience of drug treatment – not substitution
   a. accessing service
   b. attitude of staff
   c. peer support
   d. consultation – input into treatment plan
   e. impact of regulations (inc. monitoring)
   f. relationship with health professional
   g. disclosing/discussing mental health in AOD setting
   h. access to mental health services
   i. access to other services
   j. what it's like for me (personal impact)

10. General Practitioners
    a. trust/disclosure
    b. experience of discussing drug use
    c. experience of discussing mental health

11. Hepatitis C
    a. experience of hepatitis C
    b. impact on drug treatment
    c. impact on mental health
    d. other

12. Complex vulnerabilities
    a. impact on drug treatment
    b. impact on mental health
    c. Centrelink/welfare/DSP
    d. debt
    e. housing
    f. employment
    g. family
    h. relationships
    i. physical illness
    j. crime/gaol/criminal record

Appendix F –
Service provider interview schedule

Preliminaries:

- Collect/confirm background details i.e. name (collect only first name on tape)
- Organisation
- Position in organisation
- Type(s) of treatment/services offered
- Length of time in AOD/mental health fields
- Time working with clients with comorbidity (drug use and mental health problems)
- No. of clients seen (if appropriate)

Questions/topics for discussion:

1.   Definitions of treatment
Could you define your services' view of treatment for people who experience problematic drug use? Who receives it?

2.   Treatment philosophy
Does your service have a particular treatment philosophy i.e. harm reduction, abstinence-focused? How are treatment outcomes defined by your service? What constitutes success and failure? Do you think those goals and definitions are widely held (by clients, their families, community)?

3.   Terminology
Which terms do you (or your service) commonly use to describe co-occurring drug and mental health issues i.e. comorbidity, dual diagnosis etc? How do you define these terms? Do you use these terms with clients? How are they explained?

4.   Frequency of comorbidity
How often does your service support clients with co-existing drug and mental health problems? Would you say that anxiety and depression are common problems? Are these problems expected/normalised? Are they an integral part of treatment or sometimes ignored? For what reason?

5.   Assessment
Does your service undertake or seek mental health assessments of your clients?

6.   Barriers to treatment
What would you say are the barriers to drug treatment for clients with anxiety/depression? What prevents people accessing or staying in treatment? Are these different from barriers to drug treatment in general?

7.   Incentives to treatment

What could improve access to treatment and treatment outcomes for clients with anxiety/ depression? What helps clients stay in treatment?

8.   Training/supervision

Do you or your colleagues receive any specific training or supervision or in dealing with anxiety and depression? Is ongoing debriefing or mentoring available?

9.   Characterising clients with comorbidity

Can you describe a typical client with anxiety/depression? How are clients with anxiety and/or depression viewed by your service? How are clients with these problems similar or different to other clients?

10.   Treatment services for comorbidity

What services are offered to help clients with anxiety and depression at your organisation? Would you say your service offers an integrated, parallel or sequential service for comorbidity? Do you offer additional services beyond dealing with drug use and mental health issues?

11.   Client input

How much input do clients have when deciding on treatment plans at your service? In what ways? Is client input seen as important?

12.   Links with external agencies

Does your organisation refer clients with comorbidity to other services? Under what circumstances? How do these interagency relationships work? Do you have shared care arrangements? How are these managed?

13.   Peer support/mentoring

Do clients at your service have access to peer mentoring/support? Is this/would this be useful?

14.   Stigma/discrimination

How do issues of stigma/discrimination against create particular challenges for people with comorbidity?

15.   Client confidentiality

Does your service have guidelines on maintaining client confidentiality within the service (and across shared care arrangements)? How are confidentiality arrangements explained to staff and clients?

16.   Ideal treatment

What would be an ideal treatment (or an ideal treatment approach) for co-occurring drug use and mental health problems?

Appendix G –
Key informant workshop participants

Facilitator
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Project management/research team
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