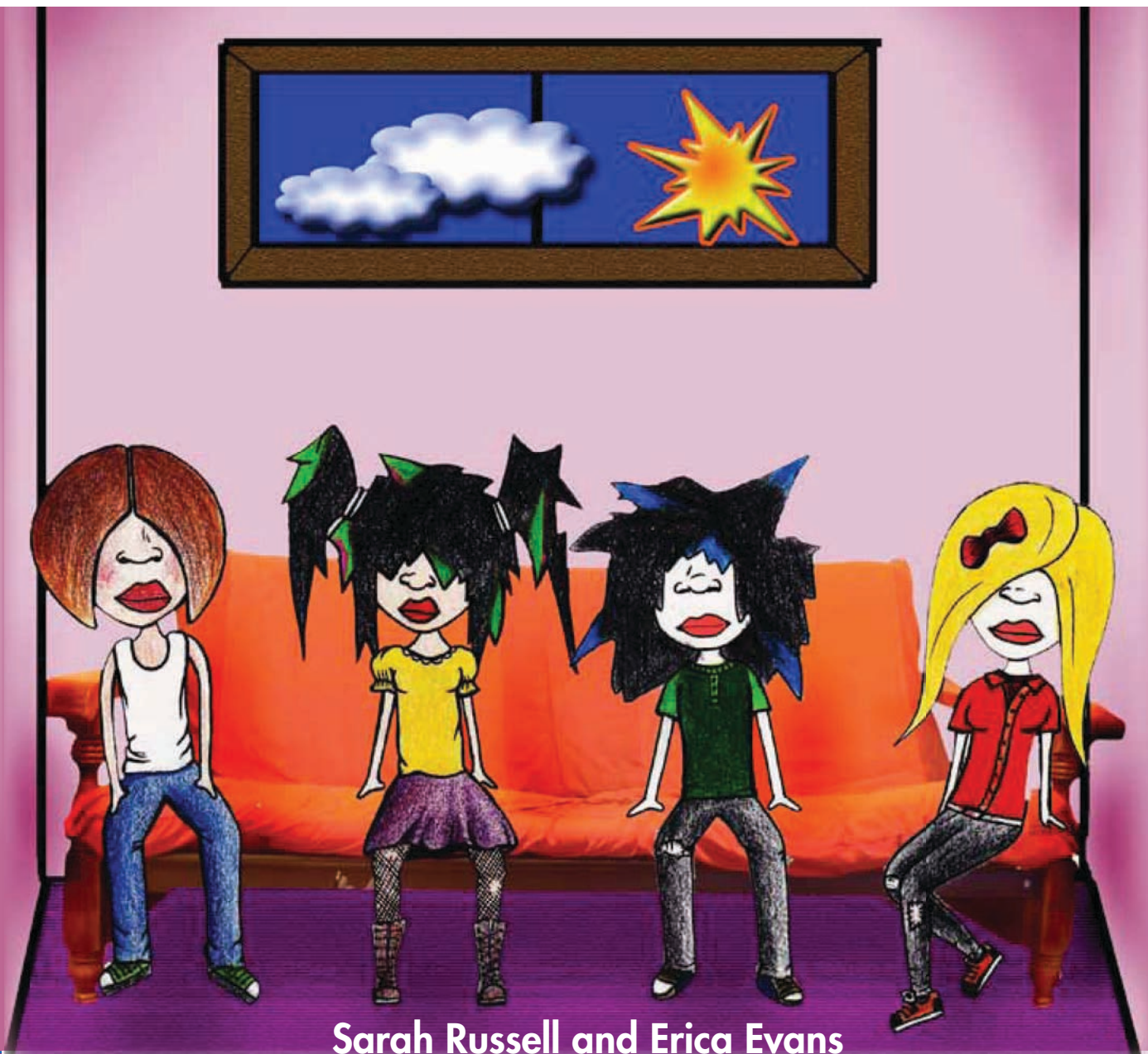


Looking beyond dual diagnosis

Young people
speak out



Sarah Russell and Erica Evans

Looking beyond dual diagnosis: Young people speak out

Research Report

2009

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Cover illustration: 'Young people speak out' by Erica Evan

Illustration on Page 39 : 'Another day, another worker' by Erica Evans

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Russell S and Evans E (2009) "Looking beyond dual diagnosis: Young people speak out"

beyondblue research report Research Matters: Melbourne

Acknowledgments

We offer our thanks to all participants for their interest in the research project and willingness to talk openly with us about issues that are important to them. We are also grateful to the youth workers who recruited participants from their respective organisations. Our thanks also to Philomena Horsley, Nina Devine and Vanessa Morphea for helping us to design the interview schedule; Drs Clare Carberry, Philomena Horsley, and Jan Browne for their comments on early drafts of the report; and Peter Wearne (YSAS) and Associate Professor Dan Lubman (Orygen) for agreeing to provide feedback on this report, and Dr Giuliana Fuscaldo for her contribution to the thematic analysis and expertise regarding research ethics.



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1 Introduction

Substance misuse and mental illness can have devastating effects on young peoples' lives. While each is associated with adverse outcomes, people who experience both substance misuse and mental illness together (referred to as 'dual diagnosis') have an increased risk of adverse consequences.

There is extensive overseas literature on dual diagnosis, and an emerging literature in Australia. This literature is reviewed in Appendix 3, with a bibliography in Appendix 4. Much of the research on dual diagnosis focuses on treatments. However, apart from anecdotal accounts, little is known about consumer views of these treatments.

It is increasingly acknowledged that effective and respectful medical treatments and services need to reflect and incorporate consumer views. Although there is now a substantial body of health research involving consumer participation, most of this research is with adult consumers. Less is known about young people's attitudes to treatment and services. This represents a significant gap in the evaluation of alcohol and other drugs (AOD) and mental health services that specialise in providing care for young people.

The current research project investigated young people's experiences of youth AOD and mental health services in Victoria, Australia. The primary aims of the current research were to:

- Investigate young people's experiences of both AOD and mental health services
- Document young people's positive and negative experiences of services
- Explore young people's views on ways in which services could be improved

- Document young people's early intervention strategies (i.e. what they do when things start to go wrong)
- Explore how young people prevent relapses and stay well
- Make consumer informed recommendations for improving youth mental health and AOD services.

Secondary aims of the study were to:

- Investigate young people's experiences of receiving a diagnosis of mental illness
- Explore young people's attitudes to taking prescribed medications.

The current research project builds on a previous research partnership with a consumer of youth AOD and mental health services (Russell, Froud and Evans 2005c). The co-researcher ensured that a rarely voiced story was heard.

This report describes the views of 23 people with substance use and mental health issues. Participants were invited to speak about their experiences of youth AOD and mental health services. They were asked what worked well (and why it worked well), what did not work well (and why not), and how they would make services more responsive to their needs. Participants were also asked to describe their specific strategies for staying well, and what they do when things start to go wrong.

This report provides feedback to all those who participated in the research. It may also provide valuable new insights of potential interest/significance to health care professionals, youth workers and policy makers. Although the findings are not representative of all young people with a

dual diagnosis, the data provides a range of views about youth AOD and mental health services. Importantly, the views are from people who have used both types of services. The views and experiences of people who have received treatment and support for substance use and mental health issues make an important contribution to the body of evidence about what is working well, and what is not.

Overview of report

The report begins with a background section describing what we know about dual diagnosis, its prevalence among young people, the relationship between substance use and mental health issues and how young people with a dual diagnosis are currently treated, including evidence for these treatments. The background section also discusses current and future directions for the treatment of young people with a dual diagnosis in Victoria, Australia. The background section concludes with a discussion of youth participation and the different ways that young people can participate in research.

The next section describes the research methods that were used in this study, including

the methodological limitations. The main limitation of this research was that participants' diagnoses were based on self-reporting.

The findings section reports on the thematic analysis of the data. The findings section relies heavily on participants' direct quotations. In order to preserve the authenticity of the 'young people's voice', the quotations retain colloquial language, including some expletives.

The findings are then discussed in relation to previous research. The report concludes with a summary of the main findings, including some useful suggestions for improving youth AOD and mental health services.

Appendices 1 and 2 contain transcripts from two interviews - one with a 16 year old, and the other with a 28 year old. These transcripts have been included to give holistic accounts of their stories.

Appendix 3 and 4 contains the literature review and bibliography. The literature review is primarily a descriptive summary of a systematic review of effective treatments for young people with a dual diagnosis. Appendix 5 and 6 contains the interview schedule and the flyer that was used to recruit participants. ❖

2 Background

2.1 What is 'dual diagnosis'?

'Dual diagnosis and co-morbidity are generic terms referring to the co-occurrence of disorders. The term 'dual diagnosis' was introduced in the late 1980s to describe people with a mental illness and co-occurring substance use disorder. The term 'dual diagnosis' is now commonly used by Australian AOD and mental health workers, health bureaucrats and academics. However, the term remains ambiguous because it encompasses people with a variety of substance-use problems and a spectrum of mental health disorders (Bender, Springer and Kim 2006). There is also disagreement about the severity of either the mental illness or substance use problem (Staiger et al. 2008).

2.2 What do we currently know about dual diagnosis?

After nearly 30 years of research in the area of dual diagnosis, several findings are now clear. Drake and Wallach (2008) and Bender, Springer and Kim (2006) summarise what we currently know about dual diagnosis.

- People with mental illnesses such as schizophrenia, bipolar disorder, and chronic depression, use alcohol and other drugs at very high rates, typically two to five times higher than individuals in the general population
- Co-occurring substance misuse and mental illness is linked with adverse consequences of many kinds, ranging from family disruptions to serious health and legal problems

- Group interventions and residential programs appear to be more effective for adults with a dual diagnosis than case management, individual counselling, and medication
- People with a dual diagnosis have low rates of treatment completion and high rates of relapse.

2.3 How prevalent is dual diagnosis among young people?

It has been reported that somewhere between 50–90% of young people¹ who have substance use issues also have mental health issues (Bender, Springer and Kim 2006). It has also been reported that substance misuse among people with a mental illness has prevalence rates over 50% (Cleary et al. 2008). Prevalence rates vary widely across epidemiological and clinical studies, depending on the way dual diagnosis was defined and what methodology was used to determine prevalence.

2.4 The relationship between substance use and mental health issues

The literature describes a 'chicken and the egg' relationship between substance use and mental illness: a young person's substance use may cause mental illness; alternatively, mental illness may lead a young person to misuse alcohol and other drugs. In cases where mental illness leads to substance misuse, alcohol and other drugs may be used to relieve psychiatric symptoms (sometimes referred to as 'self medication').

¹ The definition of 'young person' differs across studies. For the purposes of their systematic review, Bender, Springer and Kim (2006) defined young people as between 12 to 18 years of age.

The relationship between substance use and mental illness may also be indirect – for example, drug use may lead to financial difficulties which, in some cases, may increase the likelihood for problems such as anxiety and depression. It has also been suggested that both substance use and mental illnesses are triggered by common etiological factors. These have been described as biological (e.g. genetic factors), environmental and/or social risk factors, such as social disadvantages, family separation and low socioeconomic status.

Rosenthal et al. (2007) suggest that an understanding of the relationship between substance use and mental health has consequences for service delivery. They suggest that a better understanding of any causal relationship between substance use and mental illness may lead to more effective service provision. However, to date, the causal connections between substance use and mental health issues remain poorly understood.

2.5 How are young people with a dual diagnosis currently treated?

In their recent editorial, Drake and Wallach (2008) provided a useful categorisation of current dual diagnosis treatments.

1. Medical interventions – pharmacological treatments that are used to treat mental illness and addiction.
2. Psychological interventions – such as Cognitive Behavioural Treatment (CBT)
3. Social interventions – the ‘recovery-environment model’ that is based on the premise that substance use among people with a mental illness is largely initiated and sustained by environmental and social forces.

According to Cleary et al. (2008), treatment for people with both substance use and mental health issues is complicated by different approaches and philosophies among AOD and mental health services. They suggest that AOD and mental health services may differ in their theoretical underpinnings, policies and protocols. Mueser

et al. (2003) describe incompatible treatment philosophies among different treatment providers as a major impediment to the provision of services for people with a dual diagnosis.

2.6 What is the evidence for treatment effectiveness?

There is an increasing number of studies that test effective treatments for people with a dual diagnosis, though most of these studies refer to an adult population. In 2008, the Cochrane Collaboration published a systematic review of psychosocial interventions for adults with both substance use and mental illness. However, according to Drake and Wallach (2008), there is insufficient evidence on treatment effectiveness for people with a dual diagnosis. They suggest that many of the commonly used treatments have not been studied with rigorous research methodologies. They recommend research into socio-environmental interventions. “We do not gainsay the importance of biological and psychological approaches, but the most promising evidence suggests that we should direct considerably more research attention to socio-environmental [interventions]” (Drake and Wallach 2008, p192).

According to Bender, Springer and Kim (2006), simply replicating adult-oriented treatments for young people is not adequate. They argue that young people require “specialised treatment to meet their unique developmental needs” (p179). However, research into effective treatments that targets young people with a dual diagnosis is “in its infancy” (Bender, Springer and Kim 2006, p200). In their systematic review, only six studies met the inclusion criteria. They acknowledged that their systematic review included a small number from which to draw strong conclusions. However, as with other systematic reviews, potentially effective interventions that have not been tested with rigorous research methodologies were excluded in this review.

In their systematic review, Bender, Springer and Kim (2006) described non-randomised and randomised studies. Their aim was to

systematically review randomised clinical trials of interventions for dually diagnosed young people. For each of the six studies reviewed in Bender, Springer and Kim's (2006) systematic review, they asked the following questions:

- What is the evidence in support of the intervention being tested as an effective treatment for young people with a dual diagnosis?
- What degree of change is associated with the intervention?

Bender, Springer and Kim (2006) concluded that Family Based Therapy and Individual Cognitive Problem Solving were the only interventions to produce large treatment effect sizes. Furthermore, the large effect sizes for these two treatments were evident at 9 months post-treatment, demonstrating sustainability of effects over time (Bender, Springer and Kim 2006).

2.7 Service models for young people with a dual diagnosis

Historically, young people with a mental illness were treated in the mental health sector and those with alcohol and drug issues were treated in the AOD sector. Young people who experienced both substance use and mental health issues have been described as “slipping through the net” or, depending on your preference for metaphor, “falling through hoops, cracks or gaps”. This metaphor implies that young people with both substance use and mental health issues received no treatment from either an AOD or mental health service. Kenny, Kidd, Tuena et al.'s (2006) Victorian based research showed that those most at risk of “slipping through the cracks” were young people living in regional and rural areas.

Increased prevalence rates, and clinical and social concerns associated with young people with a ‘dual diagnosis’, has led to increased efforts to improve services for this group. It has been suggested that the majority of young people seeking services today are likely to have substance use problems, mental health issues, as well as a “myriad of social, behavioural, and familial problems” (Bender, Springer and Kim, 2006, p178).

The literature describes three models of treatment for young people who experience both substance use and mental health issues.

1. Serial/sequential treatment – each disorder addressed separately, one after the other, in different services
2. Parallel treatment – each disorder addressed separately, one after the other, in different services
3. Integrated treatment – treating both disorders concurrently.

It is frequently argued in the literature that sequential or parallel approaches result in less than optimum patient care. Mueser et al. (2003, p17) list the problems with sequential treatment as:

- The untreated disorder worsens the treated disorder, making it impossible to stabilise one disorder without attending to the other
- There is lack of agreement about which disorder should be treated first
- It is unclear when one disorder has been ‘successfully treated’ so that treatment of the other disorder can be commenced
- The client is not referred for further treatment

Mueser et al. (2003, p17) list the problems with parallel treatment as:

- Mental health and substance use treatments are not integrated into a cohesive treatment package
- Treatment providers fail to communicate
- Burden of integration falls on the client
- Funding and eligibility barriers to accessing both treatments
- Different treatment providers have incompatible treatment philosophies
- A client “slips through the cracks” and receives no services due to failure of either treatment provider to accept final responsibility for the client
- Providers lack a common language and treatment methodology

Mueser et al. (2003) argue that integrated treatments overcome many of the problems of

parallel and sequential treatment. They suggest that within an integrated approach, both disorders are treated as ‘primary’ and are targeted for concurrent treatment. In addition, they suggest that different philosophical perspectives of AOD and mental health workers are minimised when treatment providers work side by side. They suggest that “the need to work collaboratively as a team, and to present a consistent message to clients, often leads to compromises and gradual shifts towards shared perspectives and a unified treatment approach” (Mueser et al. 2003, p18).

Although the research literature states that an integrated system is best practice for young people with a dual diagnosis, Australian practitioners disagree about which model is best in practice (Mundy 2008). It has been suggested that the AOD and mental health services treat different subsets of young people with dual diagnosis, and this had been put forward as an argument to keep the two services separate (Mundy 2008). It is also claimed that young people with a dual diagnosis who receive treatment and support in the mental health system tend to have low prevalence mental health issues and high prevalence substance use problems (Table 1). On the other hand, young people who receive treatment and support in the AOD system tend to have low prevalence substance use problems and high prevalence mental health issues.

Table 1: High and low prevalence substance use problems and mental health issues

1. Substance use problems
a. High prevalence substance use:
i. Alcohol
ii. Nicotine
iii. Cannabis.
b. Low prevalence substance use:
i. Amphetamines
ii. Heroin
2. Mental health disorders
a. High prevalence mental health disorders:
i. Depression and anxiety disorders
b. Low prevalence mental health disorders
i. Schizophrenia, bipolar disorder, personality disorder, post traumatic stress disorder

2.8 Current and future directions in Victoria

According to Lubman et al. (2008), the current models of treatment in Victoria promote either sequential or parallel approaches. With two separate systems – one focusing on drugs and one focusing on mental illness – clients have been described as “traversing a predominantly silo-based health system” (Staiger et al. 2008, p196).

In 2007, the Victorian Government released a dual diagnosis policy: *Dual Diagnosis: Key Directions and priorities for service development* (Department of Human Services, 2007). The policy is designed to improve the treatment of people with co-occurring mental health and substance use disorders. This document promotes a more integrated approach.

This policy document promotes “effective partnerships and agreed mechanisms that support integrated assessment, treatment and care” (Department of Human Services, 2007, p2). One of the policy goals in the Victorian Government’s dual diagnosis policy document is that staff in mental health and AOD services are “dual diagnosis capable”. To be “dual diagnosis capable” staff must have the “knowledge and skills necessary to identify and respond appropriately to dual diagnosis clients” (Department of Human Services, 2007, p2).

The Victorian Government’s Dual Diagnosis Action Plan 2007–2010 states that by June 2008 all people seeking assistance from services will be screened for mental illness and problematic substance use using an accepted screening approach (Victorian Government DHS 2007). A number of screening tools have been found to reliably detect substance use disorders among individuals with a mental health issue (Dawe et al., 2002). However, until recently, mental health assessments were not routinely conducted within AOD services (Lubman et al. 2008). This may be due, in part, to disagreements about the appropriateness of available screening tools within AOD settings (Hides et al., 2007). Hides et al. (2007) developed a mental health screening tool for implementation in Victoria in 2005. They also introduced CBT training, staff training

(i.e. secondary consults with a psychiatrist) and psychiatric support to GPs. Attitudes of AOD workers to these interventions were described in our previous research at Youth Substance Abuse Service (Russell, 2005b).

The Dual Diagnosis Action Plan 2007–2010 also states that by 2010 all staff in both mental health (clinical and PDRSS) and AOD services will be appropriately educated.

2.9 Youth participation in research

The National Health and Medical Research Council (NHMRC) *Statement on Consumer and Community Participation in Health and Medical Research* (2005) refers to “those most affected and intimately acquainted with the issues” as providing important insights into health research.

There are different ways that young people can participate in research. Historically, ‘youth research’ was undertaken on young people – young

people were observed, surveyed, tested, measured, and analysed by adult researchers (Checkoway and Richards-Schuster 2003). More recently, adult researchers have been encouraged to ‘consult’ with young people. Checkoway and Richards-Schuster (2003) describe young people working as ‘consultants’ who may review the wording of interview questions, recruit respondents, participate in focus groups, and comment on drafts of research reports. However, they argue that young people are rarely genuine research partners.

According to Kirby (2001), a respectful process of working with young people as genuine research partners enables the collection of rich data. Kirby argues that young people have the ability of talking the same ‘language’ with other young people, are able to talk with peers about ‘taboo’ subjects, and ability to share common experiences. In addition, Kirby suggests that young respondents may feel less intimidated by young researchers. ❖

3

Methods

3.1 Ethics

Research Matters ensured compliance with accepted ethical research standards by establishing an ethics review committee and steering group. This ethics review committee and its review processes were based on the NHMRC's national guidelines for non-institutional ethics review (NHMRC National Statement 2007). The members of the committee are experienced current HREC members and reviewed the project's methodology to ensure the protection of the interests of both the research participants and the co-researcher.

3.2 Co-researcher

A person with personal experience of both youth AOD and mental health services was employed as the co-researcher. A mentoring relationship, involving development of skills and confidence to undertake research, enabled the co-researcher to make a significant contribution to the research project. The co-researcher contributed to the research proposal and worked with the steering group to design the interview schedule. She also recruited participants that would otherwise have been difficult to access, undertook interviews and contributed to discussions that informed the analysis of data. In her role as interviewer and researcher, the co-researcher minimised the power imbalances that often exist between researcher and participant, especially those that can manifest due to differences in age and life experiences.

3.3 Recruitment

Three techniques were used to recruit participants: purposive sampling, snowball sampling and

advertising. The aims of recruitment were to include people with both substance use and mental health issues and with experiences of youth AOD and/or mental health services.

Both current users of youth AOD and mental health services and also those who had 'exited' services after reaching the 'cut-off' age were recruited. Our rationale for recruiting participants who were no longer eligible for youth services was to provide some comparison between youth and adult services. We also hypothesised that people with the 'benefit of hindsight' may provide different insights on youth services from those currently using these services.

Ten participants were purposively selected by the co-researcher and one participant was purposively selected by the researcher. Later in the recruitment process – when the co-researcher had further developed her interviewing skills and confidence – a flyer advertising the research was designed (Appendix 6). This flyer and a plain language statement were distributed to youth workers at two services, one in the outer and the other in the inner suburbs of Melbourne. Youth workers at these services organised nine interviews, though three of those recruited by the youth workers had used only one type of service. The co-researcher also spent a day at the youth service in outer Melbourne where she recruited an additional three participants via a snowball technique.

3.4 Sample

The sample comprised 14 females and 9 males, with ages ranging from 16 to 30. The mean and median age was 23.

Twenty (20) participants had used both AOD and mental health services; 2 participants had used only AOD service and 1 participant had used only a mental health service. Twenty one (21) participants were voluntary users of the services while 2 participants had been ordered by the justice system to use services.

Participants described using the following types of services:

Alcohol and Drug Services

- Youth Substance Abuse Service (N = 7)
- Turning Point Alcohol and Drug Centre (N = 6)
- Eastern Access Community Health alcohol and drug team (N = 4)
- UnitingCare Moreland Hall (N = 2)
- Eastern drug and alcohol service (N = 2)
- Youth Northern Outreach Team (N = 1)
- Windana drug and alcohol recover (N = 1)
- Tandana Place (N = 1)
- Odyssey house (N = 1)
- De Paul house (N = 1)
- Aboriginal Health Service (N = 1)
- Westernport Drug and Alcohol Service (N = 1)

Mental Health Services

- Hospital inpatient (N = 11)
- Orygen (N = 8)
- GP (N = 7)
- Community health counselling service (N = 7)
- Crisis and assessment and treatment (CAT) team (N = 4)
- School/University counsellor (N = 4)
- Child and Adolescent Mental Health Service (N = 3)
- Private psychiatrist (N = 2)
- Private psychologist (N = 1)

Dual diagnosis services

- Connexions (N = 4)

Participants' self-disclosed diagnosis of mental illness included:

- Depression (N = 10)
- Bipolar disorder (N = 5)
- Schizophrenia (N = 4)
- Anxiety (N = 3)
- Post traumatic stress disorder (N = 2)

- Borderline personality disorder (N = 3)
- Attention deficit/hyperactivity disorder (N = 2)
- Schizoaffective disorder (N = 1).

Participants were not asked to disclose their drug use, though some participants volunteered this information.

Table 2: Participant demographic details and mental illness diagnosis

Participant Number	Age	Sex	Mental illness
1	24	F	Depression
2	23	F	Bipolar disorder
3	16	M	Post Traumatic Stress Disorder (PTSD)
4	28	F	1. Anxiety 2. Depression
5	22	F	Schizophrenia
6	25	F	Schizophrenia
7	23	F	1. Depression 2. Personality disorder
8	24	M	1. Attention deficit/hyperactivity disorder (ADHD) 2. Bipolar disorder.
9	30	M	1. Depression 2. ADHD
10	30	M	1. Schizophrenia 2. Personality disorder
11	26	F	1. Schizophrenia 2. PTSD
12	20	F	1. Anxiety 2. Depression
13	23	F	Depression
14	25	M	Not disclosed
15	23	F	Not disclosed
16	20	F	Depression
17	19	M	Not disclosed
18	20	F	1. Schizoaffective disorder 2. Bipolar disorder
19	27	M	1. Depression 2. Personality disorder 3. Bipolar disorder
20	22	F	Anxiety
21	22	F	Bipolar disorder
22	25	M	Depression
23	20	M	Depression

3.5 Data collection

Data was collected via face-to-face interviews with a semi-structured interview schedule (Appendix 5). Duration of the interviews was between 30 minutes and 2 hours. Twenty two interviews were audio-recorded and transcribed. One participant did not agree for the interview to be tape recorded – notes were taken during this interview.

Eleven interviews were conducted by both the researcher and co-researcher, 11 interviews were conducted by the co-researcher alone, and one interview was conducted by the researcher alone. Interviews were conducted at mutually convenient locations including participants' homes, cafes, public parks or youth services.

Prior to the interview, demographic information was collected. We also asked current service users what AOD and mental health services they were using, and how long they had been attending these services. For those who had exited services, we asked them what AOD and mental health services they had used, and for how long.

The interview schedule was designed to address each of the research aims. To explore young people's experiences of both AOD and mental health services, participants were asked to describe both 'good' and 'bad' experiences of AOD and mental health services. They were then asked to explain why these experiences were good, and not good. Participants were also asked to describe a "YES" and a "NO" moment"- an example of assistance from a service that was exactly what they needed, or exactly what they did not need. Participants were asked to describe their ideas for improving AOD and mental health services.

The final section of the interview schedule addressed the remaining two aims: to document what young people do when things start to go wrong and to explore how young people prevent relapses and stay well. This part of the interview focused on what participants did on a day-to-day basis to stay "on track". What types of things helped them to stay well? They were also asked to describe the type of things that they do when things start to go wrong for them, and the type of assistance they needed when things start to go wrong.

After discussions with the co-researcher and the steering committee, two additional questions that did not address our original aims were added to the interview schedule. These questions were added to further understand young people's experience of dual diagnosis. The co-researcher hypothesised that young people may not benefit from a diagnosis of mental illness and from taking psychotropic medication. These hypotheses have important implications for treatment approaches. Participants were asked to describe the impact of being diagnosed with a mental illness. For instance, how did the diagnosis make them feel? Was the diagnosis a help or a hindrance? Participants were also asked to describe how they felt about taking medication.

3.6 Data analysis

The interview transcripts were critically analysed using thematic analysis. This method of analysis is a qualitative research method that is used to generate common themes. The data from the interview transcripts were organised into a system of coded categories. The aim was to produce themes that were solidly grounded in the data. These themes were then compared and contrasted with the literature.

3.7 Strengths and limitations of the research

The 'consumer co-researcher' added significant value to this research project. During the interviews, the co-researcher and participant shared experiences and discussed issues that were important to them. The co-researcher was able to talk the same 'language' with her peers, and discuss 'taboo' subjects. The data from these 'conversational' interviews included some rich insights that might not otherwise have been captured/shared. However, genuine youth participation is time consuming. The research design underestimated the amount of time required for mentoring the co-researcher and collection of data.

A limitation of this research is that participants' diagnoses are based on self reporting. A limitation of self disclosure is that the diagnosis has not been validated. It is possible that the diagnosis may have been made by a psychiatrist, or by a GP, counsellor or other AOD or mental health worker.

It is acknowledged that our sample was biased because participants self selected (i.e. they chose to talk about their experiences of services). Our sample does not include young people who received no treatment for their dual diagnosis (i.e. those who "slipped through the cracks"). ❖

4

Findings

The findings section reports on the thematic analysis of the data. Both indented and text in “quotation marks” indicates a direct participant quotation. In order to preserve the authenticity of the ‘young people’s voice’, the quotations retain colloquial language, including some expletives. The rationale for relying heavily on direct quotations is to describe themes that are solidly grounded in the data.

The findings are divided into the following sub-sections:

1. Research participation
2. Views about services
3. Distinction between AOD and mental health services
4. Transition from youth services
5. Diagnosis of a mental illness
6. Medication
7. When things start going wrong
8. Staying well
9. Ideas for improving services

4.1 Research Participation

Several participants said that they are often asked to participate in research. They describe their participation in “bang bang surveys” as an “easy way to make money”. Participants also raised concerns about the authenticity of the data that is collected in ‘tick box surveys’.

None of the questions on the survey ever related to me, so my answers were irrelevant. I just made them up. I ticked some boxes, and then got paid. It was an easy way to make money. (Participant 2)

Rather than use surveys, our research involved face-to-face interviews. Participants were asked to

discuss sensitive issues, including illegal activities. Some participants described difficulties talking with researchers about substance use and mental health issues.

I know quite a few people who have a mental illness who also use AOD services. There is no harm in me asking them to talk with you both. But it may be hard for them to talk about these issues. (Participant 5)

To increase the likelihood of collecting ‘authentic data’, our research processes involved working with a young person with a ‘dual diagnosis’ as a co-researcher. Several participants said that talking with a co-researcher who had “been there too” was “great”.

Talking with you both was great. It was not like those ‘bang- bang’ surveys that they give you 20 bucks to do. When you are chatting, things lead to other things. With Erica here, saying things makes me think of more things. It is really good to have you both. It’s not like you’re talking with someone who has no idea – Erica has been here too. (Participant 4)

I could sit here now and tell you both my life story, but I can’t tell my counsellors. It is the way that these mental health workers speak to me. You both are speaking just like normal people. (Participant 3)

Finally, someone who understands...I have told you (co-researcher) more than what I’ve told my counsellor over all these years. (Participant 13)

Prior to their participation, participants were asked whether or not they had a ‘dual diagnosis’. However, participants did not use the term ‘dual diagnosis’. They described the term ‘dual diagnosis’ as “professional jargon”.

I have heard us described as “clients”, “service users”, “young people with complex needs” or sometimes even “kids”. I’ve never heard us called “dual diagnosis”. (Participant 1)

Why do they call it “dual diagnosis”? There’s nothing dual about it. I have problems with more than one substance. And I have more than one mental health problem. (Participant 6)

In contrast to “professional jargon”, participants used terms such as “frying myself” and “junkies” to describe their substance use. To describe their mental health issues, participants used terms such as “going nuts”, “flipping out” “loopy” and “psycho”

4.2 Views about services

When asked to describe good things about youth AOD and mental health services, two participants referred to receiving “help to get off drugs”.

(The AOD service) got me off using. They got me onto a methadone program, which involves seeing a doctor once a month. I had a caseworker as well who I saw once a month. I actually jumped off methadone on a pretty high dose and went away to my sister’s house for a few weeks. It was because I really wanted to do it. Even before I went on methadone, I didn’t want to be on it. It was the stigma of being on methadone. I was on buprenorphine for a long time first, but then I started using again and that sort of went on and off for 10 years and then I just stopped. I really wanted to be something else. I think it’s all in your mind really. There are times when you sit there and you say “yeah, I’m going to stop” but then you use the next day, but then there’s a time when you really want to stop. It happened with smoking as well - not cigarettes. Pot. I can’t give up cigarettes. (Participant 19)

One participant described improvements in her mental health as helping her to stop using drugs.

I wanted to get off drugs but AOD services just weren’t for me. I only went a few times. I felt getting off drugs was something I could do on my own. And I felt that if my mental health stuff was better, I could easily do it on my own. (Participant 13)

However, when describing ‘good’ and ‘bad’ experiences with services, most participants did not refer to changes in their substance use or improvements in their mental health. Participants mostly focused on their relationships with AOD and mental health workers. The importance of clients’ relationships with workers was a key finding of our research.

Participants described the importance of a worker establishing a ‘therapeutic relationship’ with a client.

A positive experience was of a mental health worker really connecting with me and working with me. (Participant 21)

Participants described positively workers who “worked with” them rather than “just hang out” with them.

Every time I saw my worker, she just took me out for coffee. She just wanted to hang out and drink coffee. But that’s not what I wanted. I’d say “I need help with this or that” but I never felt like I got the help. I spent two years feeling like I got nowhere. (Participant 20)

4.2.1 Good and bad experiences

This section relies heavily on direct quotations to describe participants’ views of ‘good’ and ‘bad’ experiences. Our data analysis indicates the following three main themes:

1. Relationships with workers
2. Type of treatment and support
3. Accessibility of services

4.2.1.1 Relationships with workers

Our data suggests that a key factor in determining whether a young person had a ‘good’ or ‘bad’ experience with a service was their relationships with workers. Participants described specific issues such as establishing a connection with a worker and continuity of care. Participants also discussed personal attributes of the worker such as their age and life experience. Finally, participants discussed their views about the ways in which a worker engaged with them.

4.2.1.1.1 Connection with a worker

Participants described finding a worker that they “clicked with”. Participants gave examples of having no connection with a worker, and described these relationships as generally unproductive and unhelpful.

Good experience	Bad experience
<p>You have to find the ones that you click with. <i>(Participant 13)</i></p> <p>I think the hardest thing about counselling is finding someone you have a connection with. You have something or you don't. You can't push it. <i>(Participant 7)</i></p>	<p>It takes time to build up a relationship with someone so you can tell them things. And sometimes you just don't click with a worker, and you don't want to tell that person anything. I've had counsellors and workers who I just don't like and I don't tell them anything. I wouldn't tell them anything even if I was dying. They are just not someone with whom I can relate. I'd rather have someone else. <i>(Participant 4)</i></p> <p>My counsellor was trying to push all their religious crap on me and I was just like 'fuck off'. The counsellor was a religious nut and when he'd talk to me he'd caress my leg and I'm saying to him 'err, get off me'. <i>(Participant 15)</i></p> <p>I had a worker doing everything they could for me. That included getting me work or enrolling me in a course but I hadn't told them that I didn't feel ready for that. I kind of felt embarrassed to tell them. So I don't think it's really their fault. They were giving all the help they could but if I'm not telling them everything, what else can they do for me? I might not be getting the help that I need, but it's not their fault. <i>(Participant 21)</i></p>

4.2.1.1.2 Continuity of Care

Participants described continuity of care with the same worker as important, though uncommon. Participants described feelings of rejection when a worker was replaced.

Good experience	Bad experience
<p>I see my GP every 2 weeks, religiously. He's really good. I've been seeing him for the past 5 years and he know everything that I've been through. And it's really constant, which is important. Unlike the other services that change workers frequently, he has been constant and reliable. Even if I don't need to get a script, I still go just to touch base with him. It is part of my routine. So I'm very grateful for the relationship that I have with my GP. I know that it works, and I am happy. <i>(Participant 4)</i></p> <p>I've had the same worker now for about 3 years. This is the longest I've seen anyone stick around. <i>(Participant 3)</i></p> <p>In the mental health system, their workers don't get emotionally involved, but they are still compassionate, and they can still listen and genuinely care for you. But they don't get burnt out. I saw the same mental health counsellor for two years. We became very close – she was really good and did heaps for me. <i>(Participant 1)</i></p>	<p>I had a really good worker at a service. But she wasn't there for long. I really liked her and just started to trust her and they transferred her. <i>(Participant 10)</i></p> <p>The good ones often leave. It really sucks. It makes me feel rejected. I have a fear of rejection. <i>(Participant 20)</i></p> <p>You would build up something with the worker but then you change workers. <i>(Participant 19)</i></p> <p>I've seen about 12 different counsellors. Many left after a year or so, and the rest of them I just didn't click with. <i>(Participant 12)</i></p> <p>I went through 3 different counsellors in a matter of months – one moved, the other got married, and then I had the third one who by that point I didn't want to talk to. I thought that she'd probably end up leaving as well. I have very big trust issues. And the chick I had last was kind of standoffish, she just wanted to 'get the job done'. And the one I really liked was the one that got married. <i>(Participant 13)</i></p> <p>When staff leave, it can be traumatising, particularly if you get close to a worker and they leave. Half the workers just disappear. No one tells us where they have gone. We ask, but no one tells us. We don't get closure and it really screws us around. I don't think workers realise how hard it is for us when we lose a worker and we don't get proper closure. We already have trust issues, about being abandoned. To just lose a worker and be changed to a new person, it creates issues of trust. <i>(Participant 1)</i></p> <p>There have been times with services that are very frustrating because the workers kept changing. Like the time when I went onto a criminal court order. I had to go to the Justice Centre and see a worker there, who then got replaced, and then the next one got replaced too. During the same period, my AOD worker resigned and I got a new one, and they changed my mental health worker. Within 3 months, there were 6 different workers who I had to tell my story to. <i>(Participant 4)</i></p>

4.2.1.1.3 Compassion

Participants described positively workers who genuinely care, or at least “act like they care” during their working hours.

Good experience	Bad experience
<p>It is a good experience when you find someone who genuinely cares. <i>(Participant 10)</i></p> <p>The service was like a family – it was supportive and personal. <i>(Participant 6)</i></p> <p>It was good to have someone who showed that they cared. It's just really nice to know someone cares... Even when I wasn't turning up, my mental health worker would come to my door, and I'd be hiding away. But at least I knew she cared. <i>(Participant 20)</i></p> <p>I had a good worker who took me out for walks and coffees. They didn't pressure me into talking about the actual problems in my life. They'd let it come from me. They got to know the person I am. And how I am, and when I use and when I'm not using. So they could actually see what was happening around me. <i>(Participant 20)</i></p>	<p>My own experiences with both the AOD and mental health services was that the doctors and workers had no empathy of the hardship experienced by people suffering with either problem. <i>(Participant 6)</i></p> <p>This is their job – they get paid to do it. I understand that. But they don't need to show that to me. It's like they are showing me that this is just their job and they really don't give a shit about me – they have just been told to care for a few hours. <i>(Participant 3)</i></p> <p>If they don't want to listen, then they should at least act like their listening. Or get another worker to sit down and talk with you. <i>(Participant 20)</i></p> <p>They care during their working hours. It's their job to care. <i>(Participant 1)</i></p> <p>I think I've seen about 4 psychiatrists who didn't seem overly interested or like they cared at all. <i>(Participant 13)</i></p> <p>The staff are horrible. They just didn't seem sympathetic in any sense. <i>(Participant 19)</i></p> <p>I've had nurses yelling at me, and I actually ran away once. They were being really cruel. <i>(Participant 18)</i></p>

4.2.1.1.4 Respect

Participants described the perception that workers were treating them with respect as important. Participants defined respect as “being treated like a human”.

Good experience	Bad experience
<p>I ended up doing some drugs and stuff and I ended up in hospital – the cops took me there. But, unlike my other admissions, they were very nice to me. They didn't treat me any different to if I had have gone in there with a broken leg. They treated me just like a human. They were nice. Other times, I have been treated like I was a naughty child... Some of the good experiences are that some doctors have actually listened to what's going on for me. Others just give me anti-psychotics. But a few have taken time to listen to how it is for me. <i>(Participant 21)</i></p>	<p>I am expected to sit there and open up my life to them, and I often only know their first name – or, with the doctors, maybe just their surname. I don't expect them to tell me about their whole life. But they should not be completely shut off. <i>(Participant 3)</i></p> <p>In my experience, the mental health workers are all the same – they are dismissive, patronizing, and don't seem to have human emotions. They don't talk like a human to human – they are more like a text book talking at you. I think they have all been trained to behave like that. I am sure there are some good ones out there, but I have not met them. <i>(Participant 6)</i></p> <p>The worst thing is that the mental health workers are often deceptive. They don't tell you the truth because they don't think you can handle it – so they lie to you instead. They treat me like I am a 5 year old. I think they are scared about how I will respond. <i>(Participant 4)</i></p>

4.2.1.1.5 Life experience of worker

Participants described difficulties when talking to workers with whom they did not share things in common. Participants described connecting more with workers who had ‘lived experience’ than workers who had “learnt it all from a book”.

Good experience	Bad experience
<p>A lot of the workers in AOD services have had personal experience. I think it is very important. Obviously they don't have to have been a major addict, but just for them to understand the whole addictive side of things. <i>(Participant 21)</i></p>	<p>Psychiatrists and some psychologists seem arrogant. Psychiatrists have said disgusting things to me, ridiculous shit. For example, when I was a kid my dad used to beat me all the time so I used drugs. The psychiatrist would say: “Why didn't you just call the police”. How is a kid meant to do that? I had no connection with him. In fact, every psychiatrist I've ever seen, I've hated. They have all been about text book, they don't appear to have any life experience or compassion. It's very clinical and formal. I get the impression that it is just a job. <i>(Participant 1)</i></p>

Good experience	Bad experience
<p>My current worker is pretty good with knowing what I'm on about. She's gay as well, not that that's a big deal, but she's been through shit, not quite the same as me but she knows what it's like to feel the way I do, and that helps. <i>(Participant 7)</i></p> <p>I connected so much more with AOD workers who had had past drug and alcohol issues as opposed to workers who have never had any but gone and studied. <i>(Participant 1)</i></p>	<p>They have people working there who have just read stuff in a book. They haven't lived any of what I have and they have no idea. You can't communicate with them. They have no idea and no compassion. <i>(Participant 10)</i></p> <p>These young counsellors haven't even lived life – they are straight out of university and have learnt it all from a book. I don't relate to young people who are from privileged backgrounds and have been to university. I could never go to university. Their lives are just so different to mine – they are from another world. I just don't get along with them. They just have no idea what it is like to be me – and they say such stupid things. Apparently they are trying to help me, but they make it worse. <i>(Participant 4)</i></p> <p>There was one worker who didn't have any personal experience and it was very hard for me to connect with her because she didn't understand. She would say "how come you can't just stop after five drinks?" and I'm like "well I just can't". She just didn't understand the whole thing. It was very hard to connect with her. <i>(Participant 21)</i></p>

4.2.1.1.6 Age of worker

Participants suggested that they connected more with older workers than younger workers. Participants said that older workers had more life experience.

Good experience	Bad experience
<p>The better counsellors are those that are older 35-40 – at least they have some life experience. At least someone who is a bit older than me may have had some life experiences – they may have gone through some shitty times with their kids, or something. <i>(Participant 4)</i></p>	<p>I've seen someone at a service who is an 18 year old – just a school kid – and she tried telling me how to do things. It's just bullshit. Like she has any idea of my life and what I go through. <i>(Participant 10)</i></p> <p>I've also had counsellors who are younger than me. I had this case worker, I think she was a social worker – she was really young which I found insulting. <i>(Participant 4)</i></p>

4.2.1.1.7 Workers' advice

Participants said that they did not respond positively to workers who “knew what was best for them”. However, participants said that they appreciated being given “good advice”.

Good experience	Bad experience
<p>Someone to talk to who knows what they are talking about. <i>(Participant 10)</i></p> <p>Every now and then a worker might say something that makes me go, “Whoa, shit, yeah that makes sense”. I appreciate good advice. <i>(Participant 7)</i></p> <p>When you're young, people probably are doing all they can to help. But you're young, you're not going to accept the advice until you are ready. <i>(Participant 12)</i></p>	<p>When things start going wrong, I need workers who are prepared to listen, and not to tell me how I should be doing things. <i>(Participant 1)</i></p> <p>The counsellors, doctors and nurses in hospitals think that they know what is best for me. Rather than try to work out with me what is best for me, health professionals tell me what is best for me. <i>(Participant 4)</i></p> <p>I'm one of those people who needs to work things out on my own. I need to be able to blurt shit out to someone instead of having all this shit inside my head driving me crazy. So I don't really work well with people who are going to tell me what to do because eventually I will work it out myself. <i>(Participant 7)</i></p> <p>One thing that doesn't help is clichéd comments from workers. Like if I say I can't do something and they say “yes you can, you can do anything”. <i>(Participant 20)</i></p> <p>I went to a GP with my auntie and I told them how I felt. He just wanted to straight away put me on anti-depressants. He also said that he would write up a certificate saying that I won't have to work and I can just stay at home. But I didn't want to do that. I never wanted to just sit around at home. I also I didn't want to take the pills, so my auntie asked the doctor: “Does he have to take these or is there any other way?” And he said, “Are you a doctor? No, I'm the doctor”. We never went back to him. <i>(Participant 23)</i></p>

4.2.1.1.8 Power imbalance

Participant described an awareness of a power imbalance in their relationships with health professionals.

Good experience	Bad experience
	<p>When I was about 12 years old, I had a mental health worker try to put it on me sexually. I told him to fuck off. Some of these people really take advantage of their position of power. <i>(Participant 10)</i></p> <p>I had this psychiatrist who asked really inappropriate, perverted questions. He made me feel very uncomfortable. He asked about my sexual experiences. He asked me if I knew what my breathing pattern was like after I have sex. I don't know why he wanted to know this. I left the room feeling very confused. <i>(Participant 6)</i></p>

4.2.1.2 Type of treatment and support

Our data suggests that another key factor in determining whether a young person had a 'good' or bad experience with a service was the type of treatment and support provided by the service. The types of treatments discussed were medical (hospitalisation, screening tools), psychological (counselling) and social (practical support, activities). In addition, participants discussed the physical environment, other clients who also used the service and the services' policies of clients being alcohol and drug affected.

4.2.1.2.1 Social support

Participants described positively those services that provided practical assistance (e.g. help with budget, paying bills, providing tickets for public transport). Participants who were currently homeless (or had experienced homelessness in the past) described social interventions such as fresh food and showers. However, one participant expressed concern about young people becoming dependent on services.

Good experience	Bad experience
<p>It was a tight knit community and there was always fresh food, showers, and workers who would sit and listen to you and care. <i>(Participant 1)</i></p> <p>The food is great in detox. <i>(Participant 9)</i></p> <p>Good meals in there. They got the best menu in Melbourne that mental health place. <i>(Participant 11)</i></p> <p>They get to know you and what you need. And how they can help you. They have helped me with train tickets, emergency accommodation. They have helped me find jobs, all sorts of stuff. <i>(Participant 23)</i></p> <p>My worker has started to help me with my budget. I needed someone to give me some boundaries so I wouldn't spend all my money on drugs. <i>(Participant 20)</i></p>	<p>One of the bad things is that we can become dependent on the whole thing – the free food, the support and the kindness. The idea that there is always someone there. In the real world, we don't always have someone there. <i>(Participant 1)</i></p>

4.2.1.2.2 Activities

Participants described enjoying activities. They described activities as educational, fun, distracting and confidence building.

Good experience	Bad experience
<p>The good ones are services that do stuff and buy you stuff. Some have a membership to a gym and pool. They do activities – they take you out for the day. In the evenings, we go to movies. <i>(Participant 3)</i></p> <p>We would go caving or rock climbing. We used to go to movies and other outings. There was heaps of funding back then. <i>(Participant 1)</i></p> <p>Going out and playing pool and stuff. The surfing trip was pretty cool... They pay for us to go to see movies and to go to the comedy festival <i>(Participant 7)</i></p> <p>The cooking and art was good. We'd go on outings. <i>(Participant 12)</i></p> <p>Art, computers, music. I've been making dance beats lately. If I didn't have this service, I don't know what I'd be doing. <i>(Participant 21)</i></p> <p>I've also been linked in to do lots of different things around, like they'd help me get ready for uni, and they set up so I could do a CAE course which is really helpful. <i>(Participant 18)</i></p>	

4.2.1.2.3 Counselling

Those participants who had the benefit of hindsight described counselling as helpful. Most other participants described experiencing difficulties when talking with counsellors about “their stuff”.

Good experience	Bad experience
<p>At the time I would have said “no, the mental health stuff did not help me” but in the long run I think all the talking has helped. At the time I was kind of like “piss off. I don’t want to talk to you”. <i>(Participant 13)</i></p> <p>At the time the talking was pretty irritating, you get tired of talking. At the time I probably felt like it wasn’t helping, and I was just wasting my time talking. But, I had to do it, and it has helped me to get where I am now. <i>(Participant 19)</i></p>	<p>I was just at an age when I didn’t really want, or didn’t understand help. I remember going to counsellor after counsellor and it was always the same. The talking stuff. <i>(Participant 12)</i></p> <p>The only thing they do is talk to you. And what the fuck is that going to do? That’s why I stopped going, because I don’t want to talk. What can they actually do to help me? <i>(Participant 15)</i></p> <p>Workers keep trying to get me to talk about my stuff, but I’m not a talker. Perhaps finding ways to talk about all this shit would help me to get over it. But it’s the way that they approach it. When a counsellor is with you they are “a counsellor”. They say things like “and how does that make you feel?” It is so patronising. I can’t stand it. Why can’t just some normal person talk with me? <i>(Participant 3)</i></p> <p>The mental health workers tried to get me to talk with them about stuff, but I didn’t know them. They used to come into my foster parents’ home, they were very invasive trying to get me to talk about what had happened to me. I used to hide when they were coming. I was a terrified young child, and I did not want to talk about it. <i>(Participant 5)</i></p> <p>They just keep trying to get me to talk about my stuff – they need to have other ideas about how to help me. If I can’t do it that way, they need to think of other ways. There are other things that may help me, like the art therapy, but they are not willing to do it...I’m not good with talking about certain things in my life. There are certain things that I just prefer to keep to myself. I’ve always been taught not to talk with counsellors – because the police can take them to court and they have to say everything. My mum has always been running from the cops. So I’ve never been allowed to speak to anyone. My worker’s main thing has been to get me over that, and to get me to talk about stuff. But it isn’t helping. I don’t think there has ever really been a time when I’ve thought that this is really helping me. <i>(Participant 3)</i></p>

4.2.1.2.4 Hospitalisation

Participants described hospitalisation as generally a bad experience, particularly involuntary hospitalisation.

Good experience	Bad experience
	<p>The worst experience was when they put me in a psych ward. I was only 12. I would have been much better off at home. Also, when I was involuntary, I had no say on when I could get out. <i>(Participant 5)</i></p> <p>It was shit. It was needle in the arse. You wake up and it’s needle in your ass, and so on. I said I wanted to leave and they said I was being uncooperative so it was needle in the arse. And you have like 7 of them holding you down. <i>(Participant 15)</i></p> <p>When I was in the high dependency unit, they leave people in this little small area. And I just wished I could have been in the voluntary part. There’s a glass window separating the units and you’d see everyone in voluntary sort of cruising around, relaxing. And I couldn’t even have a bath without someone standing over me. I really enjoy my baths. When you’re in voluntary you can actually go up to someone and say you want to have a chat, or go sit in your room for a while and be by yourself without having people checking on you every 5 minutes. <i>(Participant 20)</i></p>

4.2.1.2.5 Screening tools

A participant described some questions asked during his assessment as “ridiculous”.

Good experience	Bad experience
	<p>Some of the questions they ask you in those psych assessments are ridiculous <i>(Participant 9)</i></p>

4.2.1.2.6 Other clients

Participants described the benefits of services bringing them together with other young people with similar life experiences. However, participants also pointed out some of the problems of meeting other young people with substance misuse issues.

Good experience	Bad experience
<p>If you are young with a drug problem, you feel alone, particularly if you don't have friends who use. I had a drug problem and I was very isolated, there was no one for me to talk to who knew anything about drugs. When I hooked into a drug service, I ended up meeting a lot of people my age with the same drug problems. Finally I could relate to someone... it helped that I felt I wasn't alone. That was such a relief. (Participant 1)</p>	<p>When I hooked into a drug service, I ended up meeting a lot of people my age with the same drug problems. Although finally I could relate to someone, I was also worse off because I now had people to do drugs with, and it introduced me to a whole new world...the drug service introduced me to other people who had drug problems (Participant 1)</p> <p>My bad experiences of mental health services are usually just the other clients. (Participant 12)</p> <p>I didn't have any bad experiences with the service itself. Just the other people who go there. I just didn't feel like I necessarily fit in there. I don't mean to sound horrible but the people there are really yobbo. Bogan-ish. Intimidating. I think the majority of people who go there don't go there for the right reasons. The methadone would just be a replacement until they could go and score later on. (Participant 19)</p> <p>I had to share a unit with another girl and she was very mentally ill and it was very difficult for us to live together. (Participant 18)</p>

4.2.1.2.7 Policies of clients being alcohol and drug affected

Although participants recognised the importance of young people who were alcohol and drug affected having “somewhere to go”, most participants said that they preferred other clients not to be stoned.

Good experience	Bad experience
<p>I still think it's good that some services let you be off your face because it shows the young people there that they have somewhere to go. (Participant 21)</p> <p>The best thing about the youth AOD services was meeting good drug contacts. (Participant 9)</p>	<p>Sometimes people come to the service really stoned and it's really confronting. I do feel a bit endangered, but the workers do their best to try to stop that from happening, and remove the person as soon as possible. Sometimes these people come in and they are really stoned and they are disruptive to the atmosphere and they seem to want attention all the time, which makes it really difficult for the others. (Participant 18)</p> <p>I wouldn't want to go to a service that let people be stoned. When I first came here I got tangled up with the wrong sort of people, and was drinking and smoking with them. I already had mates like that, who I drink and do drugs with. I don't need any more of them. I need to make friends where we can say “Let's go to the movies” and not have to drink at all. (Participant 21)</p> <p>They mix the wrong people with the wrong people. When I go for my appointment with a worker, there may be 5 or 6 other people there who are off their faces. (Participant 3)</p>

4.2.1.2.8 Environment

Participants described the importance of “having a place to go”. Two participants described difficulties with the environment when they were asked to wait to see a GP. The GP's rooms were located within an AOD service's day program.

Good experience	Bad experience
<p>Generally just having a place to be. Because I can't work, it makes it really difficult to find somewhere else to be without people distracting me. (Participant 18)</p>	<p>I was told to sit down in their Day Program to wait for the doctor, and when I walked in everyone stared at me. It would have been better to use a spare room upstairs, like a waiting room. (Participant 20)</p> <p>I was seeing my doctor at an AOD service and they told me to wait in the day program, which I shouldn't have done, because I'm not a day program person. But I did because they told me to. I went down there, and all the clients there were all off their heads, and then I really felt like I wanted to use as well. (Participant 21)</p>

4.2.1.3 Accessibility of services

Participants described some difficulties accessing services. This lack of access was mainly due to length of waiting lists, opening hours and cost. Participants also described duration of counselling appointments as too short. One participant described being ordered by the criminal courts to access services.

4.2.1.3.1 General access

Some participants described difficulties accessing services. Some participants described an expectation that clients should be able to access a residential service “just for a break from the world”.

Good experience	Bad experience
	I call the CAT team and tell them I’m suicidal, I try to get help. I ask them for help but most of the time they just don’t show up at all. I go to the hospital, and they’ll send me home. <i>(Participant 10)</i>
	I wanted to go in for a break and they wouldn’t take me because I wasn’t looping out enough. You got to be really loopy to be able to get in there. They should let me just go in there so I can just have a break from the world because the world gets me down. And you’ve got it made in there. <i>(Participant 11)</i>

4.2.1.3.2 Waiting lists

Participants described being unable to access services due to long waiting lists.

Good experience	Bad experience
	It was a really long wait to get into see them. It was a six-month wait. <i>(Participant 8)</i> I like my current doctor. My mum was so sick of me swapping doctors every few weeks. My mum just rang and rang until she spoke with him – it took her about 3 months to get on to him. <i>(Participant 5)</i>

4.2.1.3.3 Opening hours

Our data suggest that restricted opening hours were a significant problem for some participants.

Good experience	Bad experience
	My big one is just availability and access for non-normal working hour people. More than anything, I need someone who is there out of hours. But I understand no one wants to be contacted 24/7. <i>(Participant 13)</i>
	Sundays are the hardest days of the week if you’re a user. There’s nothing open. <i>(Participant 11)</i>
	I find every night after I leave this place difficult, and the weekends. <i>(Participant 20)</i> I was seeing them on a Friday and talking to them would open up a can of worms. On Saturday, there’s nothing open and I’m a mess – I feel like shit after talking to them. There’s no place to go, so I end up doing stupid things to get someone to just talk to me, like slashing up. And even when I do that and go to the hospital they just tell me to leave. There’s no one to call to just talk to. And at the hospital, you wait ten hours and they see you for two seconds, and ask you stupid questions and tell you that it’s in your head. Then I end up doing bad things to myself, like getting completely wasted. <i>(Participant 10)</i>
	I will have appointments on the Friday and talk to my worker and open up all the deep stuff and then spend the whole weekend feeling like shit and brewing on it. It should be a ‘no deep stuff Friday’. <i>(Participant 20)</i>

4.2.1.3.4 Cost

Participants described cost as a barrier to accessing services outside the public system.

Good experience	Bad experience
	<p>Once, there was a really good bloke that I met and liked. He was a psychologist who trains workers in how to help people with psychological issues. I asked if I could see him. He seemed good, and he said that he would like to work with me as a client. But he was private and expensive. As soon as I told my worker that he was private, they said no. So I had to stay with the mental health service that is not helping me. <i>(Participant 3)</i></p> <p>I tried to get a private psychiatrist, but I needed a referral, but I couldn't get one. And even if I did get the referral, I wouldn't have had the money... I needed to see a psychiatrist to work through my issues...I understand that psychiatrists have done lots of uni and they want to make a certain amount of money each year but the government needs to step in and start subsidizing so that people can afford to access to good people or to keep these people in the public system. And it's not just about psychiatry – there are other things that can help us, but they are so expensive. <i>(Participant 4)</i></p> <p>I wanted to do Art Therapy –not just to do art, but to use art as a therapy. Arts Therapy is a form of therapy that I think would really help me because I like art and the counsellors are trained to use art as a way to bring your emotions and feelings out onto a piece of paper. It might be a little expensive – like \$70 per session. And you have to pay up front for 10 sessions – that is the problem. We tried the GP referral, but the Medicare rebate does not cover it – it only covers basic counselling. The mental health service has no money to spend on anything – they might take you out for lunch if you are lucky. AOD do stuff and they buy you stuff – but it is things that they want to buy you, not things that I may want. They couldn't afford to help me with the Arts Therapy. <i>(Participant 3)</i></p> <p>Services focus more on the younger people attending. Maybe they think if you're working, you can afford to get help somewhere where it's going to cost like \$150 an hour. But I can't afford that. <i>(Participant 13)</i></p>

4.2.1.3.5 Duration of appointment

Some participants described counselling sessions as too short.

Good experience	Bad experience
	<p>The other thing that annoys me is that everything is so time constricted. It's an hour session. The last counsellor I was seeing was only doing sessions once every two weeks. And it takes me a long time to open up; I need to start off with just talking about shit. By the time I start to open up, my sessions are up. Or the counsellor leaves, and then it's too late. I know that they have a lot of other people to see, but sometimes you really need to talk to someone then and there. And if I do end up having a bit of time with a counsellor, there will be other people interrupting. It makes everything very difficult, and I end up just dealing with it myself, and sometimes that's not a good thing. <i>(Participant 13)</i></p> <p>More time should be spent with young people, even if a worker has to sit with them for five hours and smoke cigarettes until they feel better. <i>(Participant 1)</i></p>

4.2.1.3.6 Court ordered

One participant described attending a service only because the criminal court ordered him to do so.

Good experience	Bad experience
	<p>Last time, I was court ordered. I didn't want to be there. It was just a waste of both mine and their time. <i>(Participant 16)</i></p>

4.3 Distinction between AOD and mental health services

Most participants described differences between the treatment and support provided by youth AOD and mental health services. Participants said that mental health professionals prescribed medication and encouraged “talking about issues”

Mental health services just do drugs and talking therapies. (Participant 3)

Sometimes the mental health system seems to be all about medication. They push anti-depressants on you. (Participant 1)

In contrast, participants said that AOD services provided activities that “took your mind off things”.

The youth rehabs were incredible and amazing. They didn't dwell on your problems. They got you doing stuff. They were very well funded for recreational activities. (Participant 1)

AOD services take your mind off things. (Participant 3)

Participants described AOD services as “more helpful” than mental health services. One participant described being surprised by this, given that drugs are illegal.

The AOD services are more helpful than the mental health system. You would think it would be the other way around. You would think that you would be frowned upon for doing drugs and all that illegal stuff. But staff in ‘detox’ are a lot more helpful than staff in the mental health system. (Participant 5)

Another participant described workers in AOD services as “non-judgmental” regarding their substance use.

Workers in the AOD service aren't judgmental. I'd tell them, yeah I went on a binge on the weekend, and they'll be like, “yeah that's ok, we'll just keep trying”. Even if my goal was to not do that, or to have less, and I've blown my budget they don't get angry, they just keep encouraging me. Not telling me off or anything. (Participant 21)

Participants said that AOD services helped young people who were using drugs to use them safely.

If you're injecting, AOD workers supply you with needles and all the water and swabs. (Participant 20)

In contrast to AOD service's harm minimisation approach, mental health services were described as generally having a “zero tolerance” towards drugs.

It is not much help when mental health workers tell me that I should just stop using drugs. (Participant 4)

Although participants described most mental health professionals as having a “zero tolerance” to drug use, one participant described a GP who was not “zero tolerance”.

I'm on methadone, and I am supposed to be clean, but I'm not. But I use a hell of a lot less than I used to use. I now only use on a Friday and a Saturday compared to every day. And my doctor knows – not my methadone doctor but my GP that I see for my mental health. He is happy that I only use 2 days a week. He is not telling me that I have to get off it totally. He is not zero tolerance like some of the mental health people. He tells me that it is good that I am using only 2 days not every day. Unlike lots of others, he doesn't tell me that he is unhappy that I am using. Of course he says that it is not ideal, but it is a hell of a lot better than using every day. (Participant 4)

Another difference that participants described between AOD and mental health services was a different level of emotional attachment among workers.

The youth services are brilliant because the workers seem really passionate, they seem to like their jobs – they want to be there and that's really important. (Participant 1)

The mental health workers are so detached. I think they have all been told that is how they have to behave. It's part of their job description. They need to change the job description. (Participant 3)

The level of workers' emotional attachment was described as having implications for continuity of care. One participant suggested that workers who do not get emotionally involved are less likely to “burn out”. She suggested that the high turnover of workers in AOD was due, in part, to workers becoming “too attached” and “burning out”.

In the mental health system, their workers don't get emotionally involved...so they don't get burnt out... I think it is good for counsellors not to become emotionally attached. In contrast, AOD workers can get too attached and they can burn out and leave. (Participant 1)

4.3.1 Services working together

Participants described examples of AOD and mental health services working well, and not working well, together. Participants identified good communication between services as an example of services working well together.

All my workers communicate. We all have a meeting every now and then and all the workers would sit down and let everyone else know their roles and what they were doing. We all know where we stand. It works out pretty well. (Participant 20)

However, most participants described poor communication between AOD and mental health services.

This section describes services working together under the following headings:

1. Referrals between services
2. Negotiating different services
3. Capacity of services

4.3.1.1 Referrals

Participants described referrals between services. These referrals mostly involved mental health professionals referring participants to AOD services.

However, some participants said that they were referred to an AOD service as a way for mental health services to get “rid of them”. They described being told that their mental health issues were due to their drug use.

The cat team was ridiculous, where do I start? I was in a really bad place. I had gone off anti depressants and was suffering very bad clinical depression. I was suicidal, I had attempted it a few times over the years. I felt the CAT team were very patronizing. They would not listen, they would tell you. It was very rushed and it felt like they did not really care. They just wanted to pass you back to AOD. So you didn't tell mental health workers that you had a drug problem. They would tell you that your depression is because you have a drug problem. Even though I knew that wasn't why I was depressed. They just want to get rid of you. (Participant 1)

One year, I had been in hospital 8 times for suicide attempts. I was mostly in for about 2 days. But then they kept me in, and wouldn't let me out. When I finally got out, I asked them if I could see a psychiatrist.

And they said that my mental illness was not serious enough for me to be in the public system. They decided that my problem was drugs. (Participant 4)

The CAT team told me that they can't help because I'm on drugs. It's the drugs that are the problem they say. And it's nothing to do with the drugs. I've felt like this forever...The mental health workers always treated me like shit. They patronize me; they just want to get me out the door. Put me on meds and shove me out the door. They just don't give a shit. They sent me to see my AOD counsellor. (Participant 10)

4.3.1.2 Negotiating services

Participants described receiving treatment and support from “a million different types of workers”. They described this situation as impersonal, messy and time-consuming.

I have a million different types of workers: AOD, mental health, DHS, Anglicare. You name it, I've got it...They have fortnightly meetings about me. I was present for one of them, and I couldn't handle it. A part of the requirements with these meetings and the documentation is that they have to shut themselves off from me – when they are writing, they are not allowed to write with any feeling towards me. So when they speak about me at these meetings, it's part of what they have to do – so I don't hold any grudges – but I am basically just an “it”. It is as if they don't know me. They all focus on bits of me. (Participant 3)

You end up with a lot of workers, and it gets really messy and time consuming. (Participant 3)

Our data identified the following difficulties that were experienced by participants while negotiating several different service systems:

4.3.1.2.1 The need to re-tell their story

I have my worker here and then I've got a psychologist, psychiatrist, and my GP. It gets tiring having to tell the same stories over and over again. (Participant 18)

Seeing different doctors, you get so sick of telling them the same stuff. (Participant 5)

How many times do I have to tell my story? I didn't mind doing it a couple of times, but having to bring 6 new people into my head was too much... I ended up asking if I could just write it and send it to Herald Sun. (Participant 4)

4.3.1.2.2 A lack of communication between services

They don't have much communication and if they do it is really brief. It seems that whatever the psychiatrist says goes, even though the young person and the AOD worker may feel that it is the wrong decision. It seems that an AOD workers word or opinion is not as good as a psychiatrist. (Participant 1)

If I don't talk to my housing worker, if I don't turn up to meetings, I could lose my house. And I have to be honest with them because if my health deteriorates then they need to be up to speed. It gets really frustrating because you tell them all your problems and they can't do anything about it. They don't talk with my counsellor or other workers. I hate that sort of a setup. (Participant 18)

My psychiatrist and psychologist communicate with each other, but the other workers don't. I have given my other workers permission to all talk to each other if they need to, otherwise there is no communication between them. (Participant 18)

4.3.1.2.3 Contradictory advice

Workers from different agencies have different methods to try to help you cope. One person tells you this, and another tells you that...and they contradict each other about what you should do. (Participant 3)

You get different advice from all the different workers, and it gets really conflicting. (Participant 10)

My doctor gives prescribes medication for my anxiety and it works really well for me. It has been one of the best things for me. So I get cross when counsellors say that I shouldn't take it. Counsellors want me to just talk and work through my stuff, but that doesn't work. I take a pill for my panic attacks, and for my depression and anxiety. The pills work for me. My methadone doctor also disagrees with my GP about me taking prescribed medication because I'm a drug addict. So my methadone doctor and counsellor are on one side versus my GP. But this medication has been the only thing to stabilize me. While I've been on it, I've made so much improvement. I'm now much more secure financially and I have bought things, and I am a bit happier. I now use drugs as my crutch a lot less...My GP went away for a few weeks and I needed a script while he was away. But the other GP would not give it to me. (Participant 4)

4.3.1.2.4 Hostility between services

It feels divided. AOD and mental health workers are from completely separate worlds – that is how it feels. I think there is a bit of resentment – it's like an unspoken war – the mental health workers think they are better

than the AOD workers and the AOD workers feel a bit invalidated/sidelined by the psychiatrists. (Participant 1)

4.3.1.3 Capacity of services

Several participants spoke positively about the capacity of AOD services for dealing with their mental health issues.

I am now seeing a doctor at an AOD service. Unlike the mental health doctor, she doesn't say that I have this mental illness because of the drugs I had taken. My first doctor said that I had drug induced schizophrenia. But I had it before I started using drugs and alcohol. But when a doctor tells you something, you listen because they are a doctor, and you don't know. (Participant 21)

In contrast, some participants spoke negatively about the capacity of mental health services for dealing with their drug addiction.

And she kept telling me that my problem was that I was addicted to heroin. And if I stopped using, I would be OK. But they told me that I had post traumatic stress disorder and generalized anxiety disorder and depression and panic attacks. So it wasn't just the heroin that was making me mental. The heroin was helping me. (Participant 4)

Some participants indicated that they preferred to talk with AOD rather than mental health workers about their mental health issues. This suggests that the AOD service had the capacity to respond to clients' mental health issues.

If you're depressed, you want to sit down and talk to someone. I connected so much more with AOD workers than mental health workers, particularly those who had had past drug and alcohol issues as opposed to workers who have never had any but had learnt it all from a text book. (Participant 1)

4.3.2 Integrating services

One participant said that it would be “confusing” to integrate services. She described a positive aspect of having many different workers as people to “hang out with”.

I think they should keep it separate. Because AOD is AOD. And the same with mental health. I think it would be confusing to bring the services together... And with all the appointments, it is something to get out of the house for... Some of my friends have an AOD worker, mental worker, psychologist, psychiatrist, housing worker, DHS workers, employment worker. That's would be good for

me because I get pretty lonely. I don't know that many people in Melbourne. And some days I don't know who I am going to hang out with? What am I going to do? (Participant 20)

However, most participants suggested that it would be beneficial to either combine services or have the different services at the same location.

With all the different agencies – AOD, mental health, housing, Centrelink – it becomes such a bureaucracy we have to deal with. It becomes impossible trying to negotiate all these different people. And having to tell your story so many times becomes really draining. There was a good period when my AOD worker was based at the same clinic as my GP. And my GP and AOD worker would talk with each other. So I was relieved that I did not have to repeat things. I gave them permission to discuss my case with each other. I would go to see my doctor, then straight after go to see her – one place, one morning. Not go here Tuesday morning, there Wednesday afternoon, there Thursday. Go to bloody Croydon this day. (Participant 4)

There's a bunch of different workers and one person deals with that thing, and another person deals with that thing and this thing. And they all say that they have not got enough funding. The DHS has to fund this organisation and that organisation and that one and that one and that one. (Participant 3)

4.4 Transition from youth to adult services

Older participants described their transition from youth to adult. This transition was described as abrupt and difficult.

I was a client of the mental health service until I turned 18. And then they said "seeya later, you're too old to see us". (Participant 15)

Another thing that annoys me is the cut off ages. You turn 25 and that's it. It's sort of sudden and you're like "oh my god what I do?" (Participant 19)

My problem was there was no transition between youth and adult services. Your youth worker might make an appointment for you at an adult service but that would be it. You're on your own two feet. You get dependant on the day program. What do you eat after that? Who do you talk to? (Participant 9)

Participants described some of the differences between youth and adult services.

You're only allowed something like 7 to 10 days at adult. You don't go out bowling or to the movies or go carting... its fucking shit. You're not allowed phone calls. You're not allowed out what so ever. It's way different to what we were used to at youth services. We were spoilt there, got bought clothes and everything. I reckon there's a lot more funding in youth alcohol and drug services than in adult services... the rules are heaps different, stricter in adult. And you don't really get to know the workers as much because you're not there long enough. So they don't try to build a relationship with you because they know you'll be gone within 7 to 10 days. Whereas at the youth service, the workers worked on building a relationship with you because they knew you were around for a fair while. (Participant 9)

The change from youth detox to adult is disgusting. That needs to change... Youth services are so good, the workers are passionate then you get to adult services and the workers don't give a shit. They treat you differently; there are no recreational outings, nothing. You're an adult now, and if you're not going to stop, then bad luck. The transition to adult services is too extreme. (Participant 1)

Participants described the cut off age of youth AOD services as "too low".

When I was 18, 19, I wasn't really at a stage when I wanted to get off drugs. It wasn't until I was about 21 that I was serious about giving them up, but I was told that I was too old for youth services. 21 or even 25 is way too young to be sending us to the adult detox places. Once you're over the cut-off age for youth AOD services, it's like a barren desert. To get help, I have to go to places with 45 year old booze heads who are just out of jail. Those sorts of places are not good for me. So I refuse to go to places like Odyssey House – I don't want to be around those kinds of people. And there is such a long waiting list anyway, and when you get in you're lumbered with some 45 year old who just got out of jail and has 10 kids. She's in a different world. Do they want to make me worse? (Participant 4)

Participants said that there was a need for exit plans from youth services.

When I turn 18, I will no longer be in DHS care. And that means the day you turn 18, get the fuck out of my house. You have to leave their property the day you turn 18. 18 is the cut off age, and they can't help you anymore. I'm working on my own exit plans – trying to save enough money. But it is hard not having any money to save. (Participant 3)

A participant described being able to continue to see youth workers after she had passed the 'cut-

off' age. She describes this flexibility as a positive feature of the AOD service.

I've had to leave the youth service but I still have a very strong connection with AOD workers that I've had in the past. I don't see them very often, but I know if I ever needed to I could. So if I feel like shit and really need to talk, I've still got them. I see a worker once every few months, out of the blue, but only if I really need to. The AOD workers do both AOD and mental health. Even though they are AOD workers, I will go to see them if I am having a shit time. If I'm stressed and need to talk. It doesn't necessarily have to be about drug issues. Some of them see me outside work hours, they don't seem to mind. I've been using the service for a long time and I've had a relationship with some of the workers for a long time. So they are pretty good with me. (Participant 1)

4.5 Diagnosis of a mental illness

Twenty (20) participants disclosed their diagnosis of mental illness. These participants were asked to describe the impact of having a diagnosis. Some participants said that having a diagnosis was helpful, other described a diagnosis as unhelpful.

4.5.1 Diagnosis was helpful

Several participants said that the “diagnosis made sense”.

The diagnosis made sense. (Participant 7)

I already knew I was anxious and depressed. I guess it is good to know though... It seems like everyone I know has depression and anxiety. I don't know many people who don't have at least one of them. (Participant 12)

Some participants said that the diagnosis was helpful for improving relationships with family members.

When I was quite sick last year, it was the first time I'd ever been diagnosed by mental health service. My dad said that I needed to see a psychiatrist and to me seeing a psychiatrist seemed like a big thing because only the really weird people go and see a psychiatrist, but eventually I did and I went into hospital the next day so it was really helpful. And my psychiatrist has been really fantastic and I've had her from the start... My mum used to get so upset when I'd be acting all bipolar, and she didn't know what it was. She used to get so upset because I would get in such rages or so hyper. So the diagnosis helped. And now they've done some of their own research on bipolar disorder. They have met my doctors. (Participant 18)

The diagnosis helped me understand. It made me feel weird but it helped me get back with my family. They explained what was going on with me, and that I had been diagnosed with ADHD and bipolar disorder, and how to help me. My mum now understands. I'm now back living with my family. (Participant 8)

Some participants described their diagnosis as helping them to understand both their condition and themselves better.

With the post traumatic stress disorder, it was a chance for me to say that I have this problem and to name the event that caused it. So it helped me to deal with the event that caused the disorder because obviously it was still causing me a lot of grief. Also, knowing that I really do have depression was helpful. Now when I am having a shit day, and feeling like shit, I know it's part of my illness. It helps me to handle it a bit more. So now when I feel like shit, I might try going for a walk to clear my head, or do some stuff to take my mind off it. Before I didn't know what was wrong with me and it was difficult to see any light. I didn't understand that I had a condition that was caused by this and that there was something that I could do about it. It was just a big dark blur that never ended. (Participant 4)

Getting a diagnosis was like I knew me a bit better. (Participant 11)

One participant described the diagnosis as helping her to join a group with others who have the same diagnosis. She also described psychosocial rehabilitation.

When I got my diagnosis, I was really relieved, because it actually meant that I had a reason for what was going on. And I've only been involved with mental health services for a bit over a year now, and it's changed everything. Having a diagnosis really helps because once you know what you've got, you know how to treat it. I'm about to start a group therapy, and I can't wait, to do it, because I want to talk to other people about what they find difficult and all that sort of stuff. And to see how they cope and what stage they are at compared to me. There might be someone there who is working, and I'll think “Wow. I want to know how you got there”. (Participant 18)

One participant described his frustration at not being diagnosed earlier.

The counsellors at school had no idea at all what was going on with me... They kept telling me there was nothing wrong with me. I'd tell them how I felt, but they just kept telling me there was nothing wrong. It wasn't their place to say there was nothing wrong with me.

They were just general school counsellors. And I went to three different schools and saw counsellors at all of them. So I don't see how they missed that there was something wrong. (Participant 8)

4.5.2 Diagnosis was unhelpful

4.5.2.1 Not understanding the diagnosis

Some participants described not understanding what the diagnosis meant, or how the illness could be treated and managed.

It made me confused. It was like "what the fuck do I do from here?" It's not like psychosis where they give you a drug. Most people don't get over borderline personality disorder till past their 40s and that involves intensive counselling and antidepressants (Participant 7)

I was diagnosed with severe bipolar, severe anxiety, and drug induced schizophrenia symptoms. I know what bipolar is, but I don't know what 'severe bipolar' is or 'severe anxiety'. I just can't get my head around it. I don't know what it means. Who put severe in front of it? What are they trying to say? Before it was just bipolar. Now it's severe. Instead of saying it's hot outside, they are saying it's very hot. So I don't know. I don't really understand it. Obviously it's worse. I've never been told a lot about bipolar symptoms or schizophrenia symptoms. All I know is bipolar is up and down... Everyone seems to have had the same sorts of experiences with the mental health services. We talk together about how they label us, and how if you have depression, they just hand out all these meds. They don't talk to you about why you have it. They just label every one, and they are not helping to tackle the causes of it all, or to even explain what it is that people actually have. They tell you what it is but they don't explain it... my doctor told me once I stabilise on my meds, we'll start talking about it, and how to cope with it. But my AOD worker is coming up with ways for when I feel like shit, and what things I like to do that make me happier. (Participant 21)

I definitely think there is that circumstantial kind of depression. But when you actually have clinical/major depression, you have people saying it's circumstantial. My mum says that. With me, everything can be going great in my life but I will still feel the same. And then I'll do the whole self-sabotage thing. My mum doesn't really believe in depression. (Participant 13)

4.5.2.2 Different diagnoses

Several participants described receiving different diagnoses. This may suggest that the diagnoses were made by a range of different health care

professionals (e.g. GP, psychiatrist, counsellor) or that those who diagnose did not always agree about the diagnosis.

I've been diagnosed with border personality, depression, anxiety, mood disorder...I don't quite get how they can diagnose everyone with so many different things. (Participant 20)

Everyone I've seen has a different diagnosis. It ranged from depression to personality disorder to even bipolar at some stage. Just everybody had a different opinion. (Participant 18)

4.5.2.3 Diagnosis as a label

Some participants described not liking a "label".

I don't really like the whole label thing. (Participant 15)

You kind of just feel like they are labelling you so they can get paid. (Participant 20)

I'd tell people about my diagnosis and they would say to me "People will put labels on you, but you don't have to worry about it". (Participant 7)

I lived in a Christian community where they called me an alcoholic. I don't like that word. I think it's a very bad word. When people call you an alcoholic, they are defining you as an alcoholic. But that's not who you are, it's something you suffer with. Alcohol has nothing to do with who you are. And when I hear the word alcoholic it makes me angry. (Participant 21)

I felt in those days when I was using the services that I was not understood but rather categorised in a small little box where I felt trapped and then would isolate through the lack of understanding. (Participant 6)

One participant said that a diagnosis did not need to be a label, nor does it mean you are "doomed forever".

A diagnosis is good and bad. I was told I had clinical depression at thirteen, and it was a relief. I was put on anti depressants straight away. It was good to know what was wrong with me. But as I've grown older and a bit wiser, I see that it doesn't have to be a label. If they tell me that I have clinical depression, does that mean that I am going to have it forever? People think they are going to have to take anti depressants every day for the rest of their lives. And that is what I thought for seven years, now I've been off them for two years, and I'm absolutely fine. I would not say I had clinical depression anymore. People think once they've got it, they've got it. So a diagnosis is both good and bad. It helped back then

but doesn't help now. A diagnosis doesn't mean that you're doomed forever. (Participant 1)

A participant said that she no longer thinks about her diagnosis.

Now I just don't think about it. I just do my own thing. What's the point of thinking about a label? All I can do is concentrate on what I'm doing now and making sure that I keep my head straight and try not to fuck up. (Participant 7)

4.6 Medication

All participants described being prescribed medication. However, only two participants said that they currently took their prescribed medication.

4.6.1 Taking prescribed medication

The two participants who complied by taking medication had been prescribed medication by a psychiatrist – and they both suggested that only psychiatrists should prescribe medication for mental illness.

GP's should not be able to prescribe medications for mental illnesses. If someone is going to give me medication to take for a certain illness, I want that person to be trained and fully qualified in whatever area that the illness is in. (Participant 21)

One participant described some of the difficulties that she experienced when taking medication to treat her mental illness.

It gets embarrassing though when I'm out, because I always have to take my pills with me, and people sort of look at me like they think I'm taking drugs. (Participant 18)

In addition to embarrassment, this participant has also experienced a number of adverse effects.

I've had heaps of trouble with the actual pharmaceutical drugs. I'm just one of those people who get side effects from everything. So I have to go on one now that doesn't have any side effects other than weight gain. Otherwise I was getting lockjaw, the shakes, restlessness, and blurry vision. I was taking the meds and then I'd get side effects, then I'd have to take another medication which reduced the side effects but had a set of its own side effects. That's why I had to go to hospital because none of the meds were working and I just felt like half of a person. I couldn't do the things that I wanted to do. (Participant 18)

Participants disagreed about the impact that prescribed medications had on their creativity. One participant stopped taking prescribed medication because of perceived impact on her creativity.

I was very big on my drawing and writing, and I was going to some pretty dark places, and sadly, that was some of my best work...The problem was though that I wasn't able to function properly at school, so I started on anti-depressants and that kind of killed the whole creative side. So I've kind of just weened myself off them. I'd rather deal with the bullshit... I gradually just lowered my dose, and then stopped. (Participant 13)

Another participant described the prescribed medication as helping her to “see more clearly”.

Taking medication makes me see more clearly and my head makes more sense. There are not as many racing thoughts. I would admit though, when I'm in a really hyper mood I can be really creative. (Participant 18)

4.6.2 Not taking prescribed medication

Most participants said that they did not take prescribed medication despite workers encouraging them to take it.

I hate it. I don't take it. Workers try to push it on me. (Participant 7)

They put me on meds, antidepressants, but I refuse to take them. After what happened to my friend. I spoke to him a couple of weeks after he was put on them and he seemed fine. The then next thing I knew he had topped himself. I just refuse to go near them. (Participant 9)

I don't take the medication. They give it to me but I don't take it. Some of them make you feel worse – they give you really bad side effects. (Participant 10)

I was on Zoloft. I was on Zoloft and Ritalin at the same time and it was a very bad mixture. It just turned me into a zombie, so I stopped taking it. (Participant 12)

I didn't want to take medication, but my mental health worker kept saying “you have to do it, you have to do it”, so I ended up just doing it to prove a point really. I took it for a few months and all it did was make me sleep. So I just stopped. (Participant 15)

I've been on Zoloft before but I didn't really take enough of it for it to work. (Participant 16)

You get used to taking medication and think you have to take it forever to stay normal. So you feel a bit doomed and learn to live with it but you shouldn't have to learn

to live with it because things change. I got to a point where I was sick of taking medication. (Participant 1)

One medication they put me on made me sleep for months on end. I ended up coming off it myself because my GP wasn't listening. He just told me to take it at night. And when I took it at night I would sleep till 4 in the afternoon the next day. (Participant 21)

Some participants said that they were prescribed many different types of medications. Participants said that being prescribed numerous different medications influenced their decision to stop taking their prescribed medication. A participant described feeling like a "guinea pig".

The tossed me around on 50 million different medications and treated me like a guinea pig. I felt like I was an experiment. (Participant 5)

I've had heaps of different meds. You go on one and they'll change it, you'll try that one out. Eventually it got to the stage where I just thought "I don't want meds, I don't want anything" and I haven't since then and I feel fine. (Participant 19)

They change your meds constantly. I'm always jumping off them because I'm sick of taking all these different meds. (Participant 20)

One participant described being concerned about the impact of prescribed medication on her body.

I feel like the meds that they give me, especially epilim, might screw my body up. I'm really paranoid that I am going to get all these diseases. It's going to screw up my liver or something like that. (Participant 20)

One participant described not being able to take prescribed medication whilst using other drugs.

They put me on medication, but I can't take it while I'm on heroin. You're not allowed to take them while you use heroin. If I give up the smack, I can have all my pills back. I loved my happy pills. They mellow me out. (Participant 11)

One participant described concerns about becoming addicted to prescribed medications.

If doctors give you medication, you take it, because they are doctors. I only don't take them when I forget, but that aside, I feel like they are giving me another drug to get addicted to. There was a point when if I didn't have my anti-depressant, I collapsed in the middle of the day. It was like, "oh my god I don't have my anti-depressant. Oh my god what am I going to do? Oh no, shit fuck I'm

not feeling so good". It was just because I hadn't had it, not because I needed it. It's a mental thing. It made me anxious. It made me shut down. (Participant 21)

4.7 When things start going wrong

Participants described some early intervention strategies for when they felt that things were starting to go wrong for them, including day-to-day activities.

Going out. Walking the dog. Hanging out with friends. (Participant 12)

It's good to have someone there to talk to and keep you from going off the rails. (Participant 7)

Other participants described specific strategies for when things were not going well. These included:

1. Seeking professional treatment and support
2. Seeking support of family and friends
3. Time alone
4. Alcohol and other drugs

4.7.1 Professional treatment and support

Participants described seeking professional treatment and support when things started to go wrong for them.

When things start going wrong, I need just some time out. I see my AOD doctor, or my counsellor straight away and discuss why things aren't going well and try to fix it – for example by upping my bupenorphine which would help if I feel like I'm going to start using drugs again. (Participant 1)

I get some help. Get back on methadone. Instead of using every day, I just use on payday. This is heaps better than every day. (Participant 9)

I also may need professional support. Not necessarily telling me what I should do, but giving me options on what I could do. Options calm me down. (Participant 12)

4.7.2 Support of family and friends

Participants described talking with family and friends when things started to go wrong for them.

Being able to have friends to talk to that I trust and for them to listen or give you advice. (Participant 6)

Having someone there to talk to, mainly friends. (Participant 15)

It depends on where I am at the time. Sometimes alcohol and drugs, sometimes it could be friends, or other times just myself. (Participant 13)

It helps to just be with someone, not talking, but just for someone to be around. Then other times I just go to drugs, because it gets me away from myself...A couple of weeks ago, a friend contacted my worker and said they wanted to have a chat about me, because I hadn't been myself for the past few weeks. And I never had friends who would have done that for me, and as soon as she did it, my worker wanted to catch up more. (Participant 20)

One participant described the process of begging as a mechanism for eliciting sympathy from “a lot of people who care”.

Just a shoulder to cry on. Just someone to be there. Someone to talk to. And that's what I love about begging, there's a lot of people who actually care about me. It is sad that I have to go and talk to strangers, while the workers that are paid to help me aren't there for me. (Participant 11)

4.7.3 Time alone

Participants described spending time alone and relaxing as helping them when things started to go wrong for them.

I relax, go for a walk. For instance I used to come to this park – it reminds me of my mum. (Participant 3)

Staying at home. Just in my own surroundings. I'll have a drink, watch T.V. I write a lot. I know when I want someone around, but friends sometimes think even though you're telling them that you want to be alone, that you don't want to be alone. (Participant 19)

I just go to bed. I'm really bad. I don't use any of the strategies, I just go to bed and for some reason I can just sleep all day and all night and I'm fine and the next day hopefully I'm better. Sometimes doing something arty it will help, because I've just got my mind focused on the one thing and I don't have to worry about what's going on around me. But when I'm really down everything's a drag. Catching the train is a drag, getting up and having a showers a drag, you just don't feel like doing a thing...Usually I'm by myself at home when it happens, but if I am like that when I'm around my family, it does help for them to say “C'mon, get up, we'll just watch some T.V or do some sewing just for a while”, just something really gently easing my way into the day.

But I'd probably have to go back to bed later on because I'd be exhausted... sometimes depression can just come on, it comes in waves. And I know if I have a high, then I'll be having a low the next day. I usually try to organize to be somewhere, like with a friend down the street. (Participant 18)

4.7.4 Alcohol and other drugs

Some participants described using alcohol and other drugs when things started to go wrong for them.

I start doing drugs, I get stoned, drinking, I drink every night. I just fuck myself up. Or I try to put myself in a psychiatric ward. (Participant 10)

When things start to go wrong, I smoke cones (Participant 14)

Participants described the benefits of smoking cigarettes, though one participant described a cigarette as helping for only “about 3 minutes”.

Smoking is a bit of a relief. It calms you down. If your head is going nuts on you, a coffee and smoke helps for about 3 minutes. (Participant 5)

4.8 Staying well

Most participants had difficulty answering the question “What types of things help you to stay well?” This may indicate that participants had not reflected on their ‘stay well strategies’/self management strategies. Nonetheless, the question elicited some stay well strategies such as “keeping occupied”.

For a long time, having an ongoing relationship with my AOD worker and counsellor helped me, until I found different coping mechanisms, such as the gym, a huge one for me, and my band. So I found hobbies that help me to stay well. And so I don't need as much counselling. I am lucky to have a passion for music. Music is really therapeutic for me. (Participant 1)

Trying to keep occupied – doing something that I enjoy – listening to a record or doing a drawing. Something to take my mind off how I am feeling. (Participant 4)

The doctor said that he would write up a certificate saying that I won't have to work and so I can just stay at home. But I didn't want to do that. I never want to sit at home doing nothing. I need to be doing stuff that keeps me occupied. Like working. (Participant 21)

I go and spend a lot of time with my family, just doing normal stuff like housework and farm work. (Participant 18)

One participant described his stay well strategy as “having a routine”.

Routine, consistency. I don't cope that well with change—that kind of pressure. I work at a café just doing dishes, and I find just sticking to the same things really helps. (Participant 19)

Other stay well strategies include talking with professionals and family, taking medication and exercise.

I like to talk to my mum and dad. Just tell them where I'm at. Also talking to my doctor. Exercise is good as well. (Participant 8)

Taking medication and talking to counsellors once a week. (Participant 9)

Some participants said that changing their social environment had helped them to stay well.

It used to be drugs and alcohol that kept me well, and hanging around with idiots who do crime and fuck their lives. 3 months ago, I went into detox and got clean. Since then I have been clean. And I've stopped associating with a lot of people. Stopped drinking and using any drugs. So I keep to myself a lot, and hope to get back to my brothers and sisters. If they get the slightest inkling that I am using drugs, drinking alcohol, not being at home enough, I will not be allowed to go back. (Participant 3)

All the drug and alcohol stuff I stopped when I stopped hanging out with the people I did it with. (Participant 13)

A participant also identified the importance of taking control of her mental illness.

My doctor has told me that I will always have voices in my head. So I need to just tell them to “shut up”. (Participant 5)

4.9 Ideas for improving services

Participants were asked for their ideas for improving services. Once again, their responses suggest the importance of their relationship with workers and the delivery of integrated and holistic care.

4.9.1 Type of care

4.9.1.1 Holistic

Participants recommended the provision of ‘holistic’ care.

An approach that looked at the whole of my life, not just trying to get me off drugs. (Participant 4)

One participant suggested a ‘strength-based’ approach². She suggested that workers find out about clients’ hobbies and interests.

Working with stuff that is your hobby. After you've been through a period of drug use or mental illness, you lose a sense of who you are and what you like doing and what your hobbies are, because you haven't been doing those things because you have been so consumed by either the drug use or mental illness. So it's really important to find your sense of self, and what you are interested in, and it is really important for workers in both AOD and mental health to encourage you back into those areas. Or to find ways to get back in on your limited income – to find enjoyable ways to occupy your time. (Participant 4)

4.9.1.2 Flexible

Participants said that services need to be more flexible and “do things” that fit with the client.

Mental health services need to be more flexible and do things that fit with the client. (Participant 6)

For example, one participant said that he would have preferred to undertake a course in Art Therapy rather than “talking therapies”.

I wanted to do Art Therapy – not just to do art, but to use art as a therapy... They couldn't afford to help me with the Arts Therapy. But they are meant to help me with that kind of thing – therapy and all that kind of stuff. Arts Therapy is a form of therapy that I think would really help me because I like art and I the counsellors are trained to use art as a way to bring your emotions and feelings out onto a piece of paper... They just keep trying to get me to talk about my stuff – they need to have other ideas about how to help me. If I can't do it that way, they need to think of other ways. There are other things that may help – like the art therapy (Participant 3)

4.9.1.3 Integrated care

Participants suggested that it would be easier for them if the services were integrated and staff were trained in all the different areas – drugs, alcohol, mental health, housing, employment etc.

Why not put it all together as one big organisation? All with the one lot of staff, all in the same office, all with the same money? And all the staff get trained in all these different areas – drugs, alcohol, mental health, housing, employment

² A strengths based approach operates on the assumption that people have strengths and resources for their own empowerment.

– it would be so much easier – not just for them but for me as well. I'd have one worker instead of five. (Participant 3)

4.9.1.4 Continuity of care

Participants said that it would help them if they were told in advance that a worker was leaving the service.

Maybe they could give us a few weeks' notice when workers are going to leave. (Participant 20)

One participant suggested paying workers more so that they would stay working for the service.

I'd pay staff more. Staff are really important, because when the staff are overworked and stressed you can tell, and you feel you don't want to burden them, which is ridiculous because it's their job. I know lots of AOD workers who have left because the pay is not good, and they don't get treated well enough by their management. (Participant 1)

4.9.1.5 Compassion

Some participants suggested that services would be improved if workers demonstrated more compassion and understanding about mental illness.

How would I make the mental health system better? For a start I would sack about half of the staff. I would try to make them understand. They have studied, but it seems to have gone in one ear and out the other. They don't seem to understand mental illness at all. (Participant 5)

What would make a good mental health doctor? They have to understand your diagnosis and not treat you like a complete invalid who can't think for yourself or talk for yourself. I can get quite anxious so my mum sometimes comes to appointments with me. I remember a few of them would speak to her not me. And I would get upset that they were talking about me. I think they need more compassion. I think that they need to know what they are talking about. And listen more to what the patient has to say so that they can see where you are coming from and give you the treatment that you really need. (Participant 5)

To feel understood and listened to is half the battle. (Participant 6)

4.9.1.6 Inclusion of family and friends

Some participants suggested involving family and friends in their treatment.

The staff should think about what circumstances the patient is going back to. Is there family and friends? If so, how can we include them so that it is better for the person when they go back to their lives. Even with counselling, they should be thinking about your life with your family and friends. You can't be in counselling 24 hours a day – or you can't be at Birribi for the rest of your life – you are going to have to leave at some point and go back to your life with your family and friends and all the other things in your life. (Participant 4)

Just before I went to hospital my psychiatrist introduced the topic of bipolar disorder to my parents. But we have not yet done anything together. Learning about it together would probably be really, really helpful because they just can't understand. So I definitely think it would be helpful for us to do some family counselling. (Participant 18)

A participant suggested that couples should receive assistance together.

They don't take couples into detox together. It would make it easier if I had my partner in there with me. It would help us both get through it better. (Participant 11)

4.9.1.7 Activities

A participant said that clients benefit more from doing activities rather than just “sitting around”.

Maybe workers should do some more activities instead of us all just sitting around watching T.V. or just going there for free food. Make clients do activities. Well not make them. But, give them the option. (Participant 20)

One participant suggested that workers could take a more active role.

Workers could spend more time doing stuff with us rather than sitting around, reading the paper and eating all the food. (Participant 7)

4.9.1.8 Exit plans

Participants suggested that young people need to be better prepared for when they reach the ‘cut-off’ age for youth services.

There needs to be a better exit plan for clients who have been using services for a long time. It really is a big void after you leave the youth sector. (Participant 6)

When the service is going to finish with you, even when that date is past, maybe you could still come in for a while longer, like once every couple of weeks. (Participant 20)

A participant also suggested the need for an ‘exit plan’ after discharge from hospital.

I think I should have been discharged from the psych ward with a health plan. Not just kicked out on the street with no ongoing care. (Participant 4)

Some participants suggested that young people should not be dependent on services, and needed to find support outside of both AOD and mental health services.

You have to have support in your life, not just when you are in counselling. (Participant 4)

4.9.1.9 Peer support

Participants said that a “buddy system” may help to “break down barriers” that prevent clients, particularly new clients, from engaging with services.

Let the kids have more of a say. The young people who have been using the service for years, like I did, could set up a buddy system. A lot of the new kids who come in tend to disrupt the place and they don’t want to listen to workers. So if they had young people who still had issues mentoring them, it would help a lot. (Participant 1)

I am currently doing peer support programs to help people with mental illness through personal experience of my own. The peer support program has been put together so clients don’t feel so isolated and are more likely to ask and get the help that they need... I think the most important thing is not to rescue but to give a guiding hand. Peer support is very useful because you can break down barriers. You can build new ways of interaction for these young people, based on equality that comes from being from similar backgrounds and having similar experiences. (Participant 6)

4.9.1.10 Complaint procedures

Participants described a need for internal processes to handle complaints about workers.

Youth services need formal processes for complaints. I made a formal complaint about the way a psychiatrist treated me, but it was not mentioned again, so I assume nothing was done. There needs to be mechanisms for our complaints to be taken seriously. (Participant 6)

4.9.1.11 Alcohol and drug education

Some participants suggested that schools and services should provide more ‘realistic’ information about drugs.

It would be good to get some drug and alcohol education. Maybe to talk about what drugs actually do to you. I probably wouldn’t have ever done acid if I knew what it was going to do to me mentally. (Participant 21)

The thing I find annoying is drug education in schools. They don’t tell you the good things about taking drugs, they only tell you the bad things...They need to tell it how it is. Not just to scare people into not using. (Participant 4)

4.9.2 Workers

4.9.2.1 Life experience of a worker

Participants said that it would improve services if workers had life experience and not just “text-book training”.

They need workers with experience. So they know more about what we go through. (Participant 11)

Someone with some life experience would make it better. (Participant 9)

A genuine person who has been through similar things, not just textbooks. (Participant 10)

Participants suggested that an ‘ideal worker’ would have the “personality of an AOD worker” with the “knowledge of a psychiatrist”.

It would be great if you could combine the personality of an AOD worker with the knowledge of a psychiatrist. It may then become less formal. They may even have their consultations in a coffee shop. I reckon that they need to get a bit personal with their clients – which is probably exactly what they are taught not to do. (Participant 1)

A drug and alcohol worker who knows stuff about mental health. The personality of an AOD worker. Maybe they could do their schooling for both mental health and AOD when they want to be either an AOD or mental health worker. I reckon AOD and mental health services need to communicate together better too. (Participant 10)

4.9.2.2 Education of workers

One participant suggested improving the education of AOD and mental health workers by including the ‘consumer perspective’ in their education and training.

I’d look at what they are getting taught. It would be good if they sat down and talked with us. They can have all these sciences, but they need to know how it feels. If the workers

could be trained around how a mental illness makes people feel. You can tell me what it's like to abseil, but I'm never going to know unless I do it myself. So if they had a conference, maybe about 30 of us went in and told them how it feels. Then they'd have to notice it. (Participant 21)

One participant suggested that GPs need specific training in mental illness.

I think GPs need to have a refresher course in mental health, because I had depression and post traumatic stress when I was younger and I see doctors and they said they thought I might have been depressed, when really, I should have been in hospital. (Participant 18)

4.9.2.3 Matching worker with client

Participants suggested a need for a 'no blame' process for a client changing workers when there is no connection between a worker and a client.

There needs to be a process for changing workers when there is no connection. I've been stuck with workers and they are not helping but you can't say anything because you don't want to hurt their feelings. (Participant 4)

4.9.2.4 More time with clients

Participants said that they wanted workers to spend more time with clients.

More time should be spent with young people, even if a worker has to sit with us for five hours and smoke cigarettes until we feel better. (Participant 1)

4.9.2.5 Communication between workers of different services

Psychiatrists and AOD workers should have a closer relationship – for example, AOD workers should be in the sessions that young people have with their psychiatrists. Also meeting up once a week to talk about the client and try to work together as opposed to against each other because that is what it feels like a lot. (Participant 1)

4.9.3 Accessibility

A participant suggested that services should be open 24 hours a day.

Just making them more accessible. Some kind of 24-hour thing. (Participant 8)

Participants suggested marketing strategies may make services more accessible for young people.

I reckon there should be more signs up in the street as to where the services actually are. More advertisement to actually let people know about these services and just more services to go to in general. More centres to go to get help. (Participant 10)

One participant suggested expanding the "free call" to counsellors to include phone calls from mobile phones.

It is important to be able to use those 'so called' free calls. But they are only free from landlines and not everyone has a landline. Most people have mobiles though. They need to make a free call number you can call from a mobile phone. And if they were going to do that, they'd need to make it so you could call it whether you have credit or not. I had a friend in a similar situation as me and they really needed someone to talk to but they had no money, no credit... Or they could have special phone cards that you can take to a payphone, and the calls could get billed to the government. (Participant 13)

4.9.4 Environment

Participants suggested that making facilities more relaxing may make them a more positive space.

I'd make the psych wards relaxing and peaceful. And get the workers to back off a little bit. You go more insane in there than what you do out here. If you're unwell, you have to get yourself well...I'd also make the day program more peaceful. So when visitors come through to see the GP, they don't get stared at by the clients...make it relaxed and peaceful. Maybe make it a bit more home like. (Participant 20)

I think it makes it a far more positive space if you can't come here drug and alcohol affected. (Participant 18)

Some participants described needing space to be alone, think and get away.

It would be good if there was a space where I could go for a week for some time out, not necessarily for a drug detox. Just for a break. (Participant 1)

They should let me just go in there so I can just have a break from the world. (Participant 11)

Participants suggested making the environment less formal.

Less formal, perhaps psychiatrists could have their consultations in a coffee shop. Mental health workers need to get a bit personal with their clients which is probably what they are taught not to do. (Participant 1)

Other participants also recommended that services provided facilities such as phones and photocopiers.

If services provided a telephone where I could make local calls to phone the electricity company to try to get the power turned back on, to phone Telstra or ring up the landlord to try to get an extension. Things like that would be useful. Also access to a photocopier and fax machine to help me deal with all the bureaucratic stuff that I need to deal with. (Participant 4)

4.9.5 Other ideas

4.9.5.1 De-criminalising drugs

One participant made a case for de-criminalising drugs.

I'm not saying make it 100% legal, but people who are registered addicts – similar to a methadone program. Giving us a certain amount that is clean so we don't get a dirty hit. And it would not be so expensive which would cut the need for us to commit crime to pay for it. (Participant 4)

4.9.5.2 Compensation payments

A participant suggested that government agencies should have a mechanism to prevent young people from spending their compensation money “all at once”.

When I was 18, I got \$9000 compo because my dad used to hit me. I blew all the money in two months though. They were crazy to have given me that much money all at once. \$4000 of it went on drugs. I got a laptop, a car, a slab every day, and choof. (Participant 23) ❖



“Another day, another worker” depicts a confused young person with a full calendar juggling appointments with different workers from different professions.

5

Discussion

Our findings show that the term “dual diagnosis” is rarely used by young people who access both AOD and mental health services. Rather than describe themselves as “dually diagnosed adolescents” (a term used in the literature), participants described themselves as misusing a variety of substances and having different mental illness diagnoses. They also described a range of social, economic, behavioural, legal and environmental issues. Our data supports other research findings that a “dual diagnosis” is associated with adverse consequences of many kinds, ranging from family disruptions to serious health and legal problems (Drake and Wallach 2008, Buckley 2006)

Our data indicates that young people look to services not just to ‘fix their problems’, but for support for a range of issues (e.g. health, social, economic, family, behavioural etc). Participants indicated that many of their problems arose when they were outside services – they described things ‘falling apart’ when they could not contact workers, on weekends, and after hours. This suggests that young people depend on the support provided by services.

Our data suggest that young people benefit from both AOD and mental health services even though particular aspects of individual services may not work for particular individuals at particular times. Our data suggests that a key factor in determining whether young people had a ‘good’ or ‘bad’ experience with a service was whether or not they experienced a positive relationship with a worker. Other factors that were identified include accessibility of services and the type of treatment and support provided. Our data indicate that young people seek, and benefit from, holistic and

empathic care. Most importantly, our data suggests that the type of treatment needs to be flexible and client-centred.

Relationships with workers

Our data suggest that young people benefit from both therapeutic and supportive relationships with workers. Participants said that they preferred older workers with life experiences. They also described benefitting from workers with knowledge of drug addiction and mental illness. This suggests that participants valued workers with both experience and education.

Participants described ‘bad experiences’ as mostly due to a mismatch between worker and client. Our data suggest that young people perceive a need to match specific workers with specific clients, and ‘no blame’ processes for changing workers. They also described a high turnover of workers that resulted in a lack of continuity of care. Our data indicates that young people experience difficulties when they ‘lose’ a worker. Participants suggested that the negative impact of ‘losing’ a worker may be decreased if clients were informed in advance that their worker was leaving.

Accessibility of services

Participants indicated that they wanted services to be more accessible. Our data suggest that restricted opening hours can be a significant problem– some participants indicated that the benefits of service could be undermined when services were not available. For example, some participants said that talking with counsellors on a Friday may result in them feeling low during the weekend when

services were closed. They said that this made them vulnerable to using drugs and self harm. One participant suggested a ‘no deep stuff Friday’.

Type of treatment and support

Our data suggests that another key factor in determining whether a young person had a ‘good’ or bad experience with a service was the type of treatment and support provided by the service. The types of treatments discussed were medical, psychological and social. Our data indicated the importance of services focussing not only on medical and psychological factors but also on the social determinants of health. Our data demonstrated the importance of social factors in shaping health behaviours and outcomes. Our data also indicated the benefits of a harm minimisation approach to alcohol and drugs rather than zero tolerance.

Not surprisingly, participants spoke positively about services that gave them “free stuff”. This practical assistance was important, particularly for those young people who were homeless. In addition, participants described enjoying activities. Activities were described as educational, fun, distracting and confidence building.

Participants spoke less favourably about medical interventions, particularly hospitalisation. Our data also suggests that counselling was difficult for young people. Interestingly, older participants with the benefit of hindsight described counselling as useful. This may suggest that a level of maturity is required for effective counselling.

Our data identified a paradox with treatment and support. Services often provided an opportunity for young people to meet other young people with similar life experiences, including other young people with substance use issues. On the one hand, participants described the benefits of meeting young people with whom they could relate. On the other hand, participants described the difficulties of meeting young people with whom they could misuse substances. One participant suggested that services “mixed the wrong people with the wrong people”.

In addition, participants said that they preferred services to have a policy of not allowing clients

to use the service when they were alcohol or drug affected. Our data suggests that clients who are not alcohol or drug affected experience difficulties when they share a space with clients who are stoned. One example was participants expressing discomfort about waiting to see a GP within a service’s day program.

Integrated model of care

Our data suggests that young people would benefit from a more integrated model of care. Our data supports Lubman et al.’s (2008) claim that AOD and mental health services in Victoria remain segregated and deliver “a fragmented model of care” (p255). This “fragmented model of care” was evident when participants described having “a million different types of workers”: AOD, mental health, housing, employment, general practitioner and DHS.

Participants described difficulties with a segregated model of care. They described different workers, high staff changeovers, re-telling their story, different advice, and conflicting views. They also described a lack of connection and cohesion between services and going back and forth between services. Most participants described a need for services to better communicate with each other.

Participants also suggested that mental health workers should be trained in AOD and vice versa. This adds weight to the Dual Diagnosis Action Plan 2007–2010 which states that by 2010 all staff in both mental health and AOD services will be appropriately educated in dual diagnosis (Victorian Government DHS 2007).

Most significantly, our findings add weight to the following problems with parallel treatments that have been previously identified by Mueser et al. (2003):

- Mental health and substance use treatments are not integrated into a cohesive treatment package
- Treatment providers fail to communicate with each other

It has been suggested that the AOD and mental health services treat different subsets of young people with dual diagnosis – the mental health

system specialises in low prevalence mental health issues while the AOD system specialises in low prevalence substance use problems – and this had been put forward as an argument to keep the two services separate (Mundy, 2008). Our study does not support this claim. In our study, participants described AOD services treating both high and low prevalence mental illnesses. For example, young people with mental illnesses such as schizophrenia and personality disorders (low prevalence mental illnesses) were referred from mental health services to AOD services. In addition, participants described preferring to receive treatment and support for their mental illness within an AOD service.

Falling through the gaps

Mueser et al. (2003) suggest that parallel treatments increase the likelihood of clients receiving no services due to a failure of either treatment provider to accept final responsibility for the client. Our study targeted young people who had used services and thereby excluded people who had not used services. Our data does not therefore show young people “falling through gaps”. Instead, the gaps that participants described were gaps in current services. The most often cited shortcoming in the services that was identified in our study was the lack of holistic care. This finding is consistent with previous research that argues for an integrated approach for dual diagnosis treatment.

Transition from youth services

Youth AOD services were described as more supportive and personal than adult AOD services. Some participants questioned the ‘cut-off’ age for youth services, and participants noted that the cut-off age differed among youth services. Our data suggests that young people need to develop an exit plan, particularly from youth AOD services. Participants indicated that these exit plans need to be developed in partnership with a worker and client. Participants also suggested that the exit process should be gradual – rather than going ‘cold turkey’ clients could be weaned from the service.

Improving services

The findings include a wish list for improving services – shorter waiting lists, longer opening hours and continuing care by a compassionate and knowledgeable worker. The findings also include more useful and realistic suggestions for improving services. Some of the suggestions involved improving access to services - these included increasing young people’s awareness of these services via marketing and expanding access to emergency counselling by including free calls from mobile phones.

Participants suggested including family, partners and friends in treatment. Expanding support networks to include personal support networks may diminish an individual’s dependency on professional services. Participants also discussed peer support in addition to professional support. Having both professional and peer support within a service would enable older workers (with education and general life experience) to work collaboratively with younger people (who may share specific experiences of substance use and mental health issues). This would create an environment when you had the best of both worlds.

In terms of education and training, participants suggested including the ‘consumer perspective’.

Diagnosis and medication

Although there are some methodological issues with self disclosure of a diagnosis, some participants described their diagnosis of a mental illness as helpful for both themselves and their family and friends. However, our data shows that there is a stigma associated with a mental illness diagnosis.

All participants in our sample were prescribed medications but that most did not take their prescribed medications. Participants indicated scepticism towards the benefits of medication. Our data suggests that young people may not receive adequate education about their mental illness, including the role of medication in the treatment of their mental illness.

Early interventions and staying well

Our data indicates that young people depend on services, particularly when things start to go wrong. Moreover, participants indicated that sometimes things go wrong because they cannot access a service. A significant finding from our study is that when participants were asked to share their non-service based strategies of staying well, many of them were unable to articulate any such strategy. However, when prompted, some participants did reflect on things that helped them cope, for example talking to family and friends, creative projects and being busy and connected.

These findings suggest that young people with dual diagnosis might benefit from learning to think strategically about staying well outside of services. In addition, a strength-based and empowerment approach may assist young people to become more independent of services and individual workers within services^{3,4}. Developing their own strategies for staying well may also help young people to cope when service are not available. ❖

³ The successful collaboration with the co-researcher was based on a strength-based and empowerment approach.

⁴ Strength based programs, such as the 'Stay Well Program' offered to people living with bipolar disorder (Russell 2008, 2005a), may assist young people to become more independent of services and individual workers within services.

6

Conclusion

Our project has provided many valuable insights about young people's experiences of AOD and mental health services. The findings include useful suggestions for improving these services. In addition to 'pie in the sky' suggestions that consumers commonly make for all health services – that there should be more health care professionals, longer opening hours, easier accessibility – participants in our study made some practical suggestions about how both AOD and mental health services could be improved. These suggestions might easily be incorporated into current services to make services more responsive to young people's needs.

Our data indicates that young people respond positively to services that are client-centred and focus on relationship building, empowerment, harm minimisation, honest communication and mutual respect. In addition, our data highlights the need for both therapeutic and supportive relationships.

Our data indicates that young people make a clear distinction between AOD and mental health services. Participants said that mental health professionals prescribed medication and provided 'talking therapies' while AOD services provided mostly social and support activities. These types of treatments and support are complementary.

Our findings support the transition towards delivering a more integrated service to young people with a dual diagnosis. Our data highlights many problems with the provision of parallel treatments. For example, our findings suggest that young people may have numerous different workers, each offering conflicting advice. Our

data also indicate a current lack of cohesion and communication between services.

Participants in our study spoke more favourably about the treatment and support offered within AOD than mental health services. Our data suggest that young people's attitudes about medical interventions (e.g. medication, counselling) may be related to the ways in which mental health treatment is delivered. Participants said that they were often not comfortable with mental health services and some mental health workers. They described the model of service delivery within mental health services as too formal or impersonal. Participants' comments about mental health services and staff may suggest a need to review the way in which mental health services engage with young people with a dual diagnosis.

Our study is a step towards giving voice to young people with dual diagnosis. In comparison to research with adult consumers, young people with dual diagnosis are still largely seen and not heard. ❖

7 Appendices

Appendix 1: Excerpt 1

A 16 year old boy describes his current experiences with youth AOD and mental health services:

"A good experience is the AOD service got me into a course. Through their office, they got a person who teaches hospitality to come in. There are 5 or 6 of us doing the course. It's not finished yet. We've still got one more day, when he decides to show back up. It's a certificate 2 in hospitality – front of house stuff. We have been learning a broad range of everything to give us options about our next step in hospitality.

I've got one really bad experience – I got robbed of my drugs at the office. They mix the wrong people with the wrong people. When I go for my appointment with a worker, there may be 5 or 6 other people there who are off their faces. My worker mostly meets me at home. But during my recent hospitality course, I was at the office a lot.

I've also done a detox at the resi. It is a detox, so you are not meant to do drugs. I am sure that there have been people who have, but you would get kicked out. I've been there twice, and I got kicked out once. We were going to sneak out and go to the bottle shop, and I borrowed someone's ID.

I thought detox was pretty cool. They take your mind off things – they have a membership to a gym and pool. They do activities – they take you out for the day. In the evenings, we go to movies. It's more relaxing stuff. They do the heavier stuff like counselling when you are over 18. The resi are really good at not mixing the wrong people with the wrong people. You are there for 2 weeks. But sometimes they can't help if – with new people that they don't know. Obviously it is harder to do this at the resi if they don't know you. But the outreach workers know their clients. But they are very low on funds.

More funding might make everything better – more funding might make me better! But there are other things to make it a better service. I wanted to do Art Therapy –not just to do art, but to use art as a therapy. That's to do with my mental health and AOD service – my drug and mental health issues. The mental health service has no money to spend on anything – they might take you out for lunch if you are lucky. AOD do stuff and they buy you stuff – but it is things that they want to buy you, not things that I may want. They couldn't afford to help me with the Arts Therapy. But they are meant to help me with that kind of thing – therapy and all that kind of stuff. Arts Therapy is a form of therapy that I think would really help me because I like art and I the counsellors are trained to use art as a way to bring your emotions and feelings out onto a piece of paper. It might be a little expensive – like \$70 per session. And you have to pay up front for 10 sessions – that is the problem. We tried the GP referral, but the Medicare rebate does not cover it – it only covers basic counselling.

I don't think I've had any good experiences with mental health services. They had a huge meeting – it was like a conference, and they let me display my art work. There was meant to be a prize awarded for the best piece, but they said that they couldn't be bothered choosing a winner so we all go a movie ticket. I was disappointed.

My mental health worker at the moment is alright. She's trying to help me. I'm not good with talking about certain things in my life. There are certain things that I just prefer to keep to myself. I've always been taught not to talk with counsellors – because the police can take them to court and they have to say everything. My mum has always been running from the cops. So I've never been allowed to speak to anyone. My worker's main thing has been to get me over that, and to get me to talk about stuff. But it isn't helping. Once, there was a

really good bloke that I met and liked. He was a psychologist who trains workers in AOD about how to help people with psychological issues. I asked if I could see him. He seemed good, and he said that he would like to work with me as a client. But he was private and expensive. As soon as I told my worker that he was private, they said no. So I had to stay with the mental health service that is not helping me. They just keep trying to get me to talk about my stuff – they need to have other ideas about how to help me. If I can't do it that way, they need to think of other ways. There are other things that may help – like the art therapy, or this bloke who seemed good – but they are not willing to do it.

I think finding ways to talk about all this shit would help to get over it. But it's the way that they approach it. When a counsellor is with you they are "a counsellor". They say things like "and how does that make you feel?" I can't stand it. Why can't just some normal person talk with me. I could sit here now and tell you both my life story, but I can't tell them. It is the way that these mental health workers speak to me. You both are speaking just like normal people. I am expected to sit there and open up my life to them, and I often only know their first name – or, with the doctors, maybe just their surname. The workers give me their mobile number – but that is only their work mobile, it's not even their personal mobile. I don't expect them to tell me about their whole life. But they should not be completely shut off. See how you two are sitting here with me, and we are having a conversation. It is how they talk to me. What comes out of their mouths bothers me. Like I may say "God this coke cordial is nice". A counsellor would probably say "Can we get back to the point?" The workers are so detached. I think they have all been told that is how they have to behave. It's part of their job description. They need to change the job description.

And another thing is I have a million different types of workers: AOD, mental health, DHS, Anglicare. You name it, I've got it. I've also got other appointments with doctors, and I have to go to my chemist nearly every other day. My workers have fortnightly meetings about me. I was present for one of them, and I couldn't handle it. A part of the requirements with these meetings and the documentation is that they have to shut themselves off from me – when they are writing, they are not allowed to write with any feeling towards me. So when they speak about me at these meetings, it's part of what they have to do – so I don't hold any grudges – but I am basically just an "it". I accessed some of these documents through freedom of information - because I am applying for crimes compensation and I am suing (deleted) when I am 18. Writing these documents, it is as if they don't know me. They all focus on bits of me.

One thing I've thought about with all the workers is that this is their job – they get paid to do it. I understand that. But they don't need to show that to me. It's like they are showing me that this is just their job and they really don't give a shit about me – they have just been told to care for a few hours. One thing I've always noticed is that they don't show any emotion about their own lives.

My brother died. After this, a lot of workers got fired, a lot of people got moved around. When bad things happen with these workers, they get shuffled around. If something tiny happens, and someone gets offended by it, or something big happens and there is legal action, they get shuffled around. So workers get moved, and you might think they have been fired, but they have just been moved to different place. They all just circulate. They are all just moving around, so you never have the same worker for very long. I've had one exception – I've had the same youth worker now for about 3 years. This is the longest I've seen anyone stick around. Even the big bosses, the managers, move on.

I live independently – I have to buy my own food, pay my bills do my own cleaning. There is room for other clients. And there is a lead tenant there to make sure that I don't stuff up, screw the house up, throw parties and all that. She's not there as a carer. She's just a person who I live with. Sometimes, if I am short of money, she lends me a bit of money – not a lot. And if I haven't got food, she has always got food there. I've spent time in foster care as well, and I was moved out of one of my carer's house. This guy had cameras all around the house – he had one in his bedroom and one in the lounge room. Nothing bad ever happened to me – I don't know about anyone else - but they moved us both out.

I've also met a few creepy workers in my time. A friend of mine has had workers touch her up. Awful shit, not good. Some of them are grouse – a few resi workers that I still keep in touch with after I moved out.

Something I've noticed is that there's a bunch of different workers and that person deals with that thing, and that person deals with that thing and this thing etc. And they all say that they have not got enough funding. The DHS

has to fund this organisation and that organisation and that one and that one and that one. Why not put it all together as one big organisation? All with the one lot of staff, all in the same office, all with the same money? And all the staff get trained in all these different areas – drugs, alcohol, mental health, housing, employment – it would be so much easier – not just for them but for me as well. I'd have one worker instead of five. I even have an employment worker.

I was diagnosed with post traumatic stress disorder and dysthiamia – the way that has been explained to me is it is the last step before depression. When I first started acting out – I used to cut my wrists – just superficial cuts, nothing really. I got put in a psych ward and they put me on seroquel which is an antipsychotic for people with schizophrenia. So without actually saying it, it told me that I had schizophrenia. And then they took me off the medication and put me onto something else. But I wanted to go back on it, because ever since they took me off seroquel, I couldn't sleep. And then I got a new doctor who said that I could only be prescribed seroquel if I was diagnosed with schizophrenia – you can then get the PBS script. Otherwise you have to pay the full price of \$180 for a month's worth of tablets. Clearly I can't afford it. Money comes into everything – I have to pay for everything. I have fuck all clothes at the moment – I am waiting for my DHS worker to beg their boss to let me have some clothes. I've got stuff all money – Centrelink has stuffed me around.

At the moment, I am trying to move back interstate to where my brothers and sisters are. I've been trying to do this for over a year. The services here and there keep bouncing off each other – yes, no, yes, no etc. Every time I run away to try to see my brothers and sisters, I get put into secure welfare. They lock me in a house for 3 weeks with up to 10 clients at a time. They have a jail yard. So I don't really have anything good to say about them.

I don't think there has ever really been a time when I've thought that this is really helping me. I once had a housing worker. She did as much as she could, but she didn't have enough authority to do much, or the funding to do much. All these organisations have to report to DHS. Everything has to be approved through DHS.

When I turn 18, I will no longer be in their care and that means the day you turn 18, get the fuck out of my house. You have to leave their property the day you turn 18. 18 is the cut off age, and they can't help you anymore. I'm working on my own exit plans – trying to save enough money but it is hard not having any money to save. At the end, I will get tiller money which will be about \$1000 but they hold onto it and you have to give them receipts. So really they spend it for you – you can buy a shit load of furniture or pay bond.

What helps me to stay well? It used to be drugs and alcohol and hanging around with idiots who do crime and fuck their lives. 3 months ago, I went into detox and got clean. Since then I have been clean. And I've stopped associating with a lot of people. Stopped drinking and using any drugs. So I keep to myself a lot, and hope to get back to my brothers and sisters. If they get the slightest inkling that I am using drugs, drinking alcohol, not being at home enough, I will not be allowed to go.

My brothers and sisters have pretty much being adopted out – 2 in one house, 3 in another. They have permanent care orders. If they want to, they can stop me from having access to them. My mum gets 6 hours access a year, and their dad gets 4 hours. With my mum being in jail, it is kind of understandable. I visit her when they let me. They send me interstate to see her occasionally but they say they don't have the money – they say that I only have a certain amount of holiday allowance a year and shit like that. I've even offered to pay them to take me to see her.

When I start to feel bad, I go for a walk. I come to this park – it reminds me of my mum. All parks remind me of my mum." ❖

Appendix 2: Excerpt 2

A 28 year old woman looks back on her experiences of youth AOD and mental health services:

"I grew up in a stable home, and didn't start using until I was with my boyfriend, when I was about 18. And his family are very supportive of him. When we've had nowhere to live, we've gone to live with his family – so we have never been on the streets. My parents don't like my lifestyle. They don't like speaking to me because I use heroin. We've got a bit better relationship now that I am more stable. His parents and his grandma are always there for us. If we get into trouble – or whatever happens – they'll help us out to pay the rent. They know the full picture – we don't hide anything from them – and they are very supportive. His dad died, but his grandma is very supportive. She takes us into her home, and if we have problems like the power being disconnected, she will pay to have it reconnected.

The good experiences of youth AOD services are those services that give you free stuff. Services that buy me things that I need for day-to-day living such as Safeway vouchers. These things make my daily life easier when I am trying to give up drugs. It's very hard for me to stay off drugs when everything else in my life is fucked up. It's really hard for me to stay off drugs when I've still got massive debt. If I've got no money after I've paid bills such as rent, I have no money left over to buy food. This makes me really depressed, and makes me want to go back on drugs. So when I am given Safeway vouchers, at least I can eat. One service contacted Telstra and negotiated on my behalf the bills that I had.

When I give up drugs, everything in my life is still fucked. It doesn't go away just because I've stopped using drugs. I still have the same problems that I had which is why I used drugs. I still have the same bills – I still have the debt collectors at my door. The same shitty living conditions, the same parents, the same friends who are still shooting up. So I don't suddenly have the best life just because I've given up drugs. It's often a lot harder without the drugs. I often think: "Why am I bothering?" Without drugs, I don't have much. I don't have many possessions. I don't even have any hobbies or interests. I don't even have my bass guitar anymore – I had to sell it – so I can't play my music. I don't have much to do. I basically had to start from zero again, and it is very difficult.

The youth mental health services just gave me medicine and counselling. Mental health workers told me that I should stop using drugs. I know that I can go long periods of time not using drugs, but only if I have money in the bank so that I can do things like go out to a café. If I have no money and I can't go out, and I am just sitting at home bored – I have nothing to do – no interests, no possessions, nothing.

The counsellors, doctors and nurses in hospitals think that they know what is best for me. They tell me what is best for me. For example, I was in hospital after a serious accident. I had been using heroin for a long time before the accident so I was withdrawing while I was in hospital. It had been about 12 days and I was not very well. And they told me that they would put me on methadone. I was told that I was going on methadone, and that was that. They didn't discuss the options with me, to try to see what would work best for me. They didn't discuss the pros and cons of methadone versus suboxone. It was what they thought was best, so it was what they did.

Rather than try to work out with me what is best for me, health professionals tell me what is best for me. They even tell me what lifestyle choices I should make to get off drugs. They tell me that I should get away from my boyfriend because he is the reason that I am on drugs. They tell me that we should split up. I should leave Melbourne I should do this I should do that. I get tired of health professionals telling me what I should do to get away from drugs. But I know myself best and I know what makes me use drugs, and what triggers it. I have tried to work those things out. The things that they are telling me to do are probably going to make the situation a 100 times worse for me. They tell me that my boyfriend is a bad influence on me, that I shouldn't be with him, he's making me use drugs. This is just stupid.

They say lots of stupid things. Like this counsellor who told me that she knew what it was like to use heroin because she had been on pethidine when she had her baby. Yeah like she really knew what it is like to be a heroin addict. I've also had counsellors who are younger than me which I find really insulting. They haven't even lived life – they are straight out of university. The better counsellors are those that are older 35-40 – at least

they have some life experience. As opposed to counsellors who are 24 who have learnt it all from a book. I don't relate to young people who are from privileged backgrounds and have been to uni. I could never go to uni. So I don't relate to these people, no matter what age they are. Their lives are just so different to mine. I just don't get along with them. They just have no idea what it is like to be me – and they say such stupid things. Apparently they are trying to help me, but they make it worse. At least someone who is a bit older than me may have had some life experiences – they may have gone through some shitty times with their kids, or something.

What would make an AOD service better? An approach that looked at the whole of the person's life. Not just trying to get me off drugs. Of course, the objective of these services is to get me to stop using drugs, but I really need to be prepared before I can stop using. I need to have all the other shit in my life sorted a bit before I can even think about stopping using drugs. Shit like bills and having no job, or the problems that caused me to start using, or my mental health problems. When I stop taking drugs, all those things get amplified a 100 times. The drugs suppress all that shit. When I stop taking drugs I have to deal with all the shit that I have been suppressing, and it's a lot to take on. To be with it, with all your senses, all day – to be sitting there all day thinking: "I'm poor, I have no money, I'm hungry and I can't afford to eat". But when I am on drugs I don't notice.

When I come off drugs, my circumstances depress me so much that I just start using again. I just can't put up with all this shit. I start to think "Why have I got nothing?", and it is really depressing. It is not just one aspect of my life that is fucked up, it is every aspect. I have no food, nothing to do, no money – and I can't pay the rent and I am threatened with eviction. Even my teeth are terrible. It is every single aspect of my life. I try to get off drugs – I do stuff like ring my land lord asking for an extension with my rent and he says: "No". Everything I do just gets thrown back in my face. So I think "Why bother? Where is this going to get me?"

The services need to address all these crucial issues before I can even think about stopping using drugs. They need to make sure that I have stable housing. If you haven't got stable housing, what's the point of giving up drugs? They need to check what type of house people live in. If it's a house in which everyone else uses, it is so much harder – you come home and everyone is shooting up in the lounge room. They need to check if I have any food. People can't give up drugs and then have nothing to eat for 2 weeks. When I am doing drugs, I do things like stealing chops from Safeway's. But if I make an effort to give up drugs and crime, then, if I don't have any money, I don't have any way of getting food. How can I just sit there hungry all day?

These services need to stabilise people's life before we can get off drugs. I've only ever had one worker who tried to deal with these other aspects of my life – and she was working in Justice. I told her than I was getting evicted but there was nothing that she could do to stop that happening. She told me to go to the Salvation Army to put my name down for emergency housing. It is really important that these services help you to get housing. And food. And to ask if you have bedding and blankets. And to make sure that the electricity is not cut off. Even if they help to get services. I don't have a phone, and I don't have any credit on my mobile. So if services provided a telephone where I could make local calls to phone the electricity company to try to get the power turned back on, phone Telstra, or ring up the landlord to try to get an extension. Things like that. Use of a photocopier and fax machine to help me deal with all the bureaucratic stuff.

I was never referred to YSAS. But I visited a friend at the resi a few times and I was jealous – there was all this food. And I visited her at Birribi and she stole all this stuff for me – boxes of toilet rolls – I had nothing. When I was 18, 19, I wasn't really at a stage when I wanted to get off drugs. It wasn't until I was about 21 that I was serious about giving them up, but I was told that I was too old for YSAS. I reckon that someone who is 30 still needs a place like YSAS.

21 or 22 is way too young to be sending us to the adult detox places. Once you're over the cut of age for youth AOD services, it's like a barren desert. To get help, I have to go to places with 45 year old booze heads who are just out of jail. Those sorts of places are not good for me. So I refuse to go to places like Odyssey House – I don't want to be around those kinds of people. And there is such a long waiting list anyway, and when you get in you're lumbered with some 45 year old who just got out of jail and has 10 kids. She's in a different world. Do they want to make me worse?

No good experiences of mental health services spring to mind, though the doctor that I see now is really good. He is a GP but the reason I keep seeing him is that he is nice, and he doesn't treat me like an idiot or a drug

addict. He knows that I have a drug problem as well as my mental health problems. But he still prescribes medication for my mental health problems that other doctors don't because I'm a drug addict and the drugs I need for my mental health problems are addictive. So he's alright, but all my other experiences have been bad.

The worst thing is that the mental health workers are often deceptive. They don't tell you the truth because they don't think you can handle it – so they lie to you instead. They treat me like I am a 5 year old. I think they are scared about how I will respond. I went to hospital after a suicide attempt – they locked me in a little room. The room had a little spy hatch, and I was on suicide watch - they would come in every hour to see if I was still alive. This went on all night and it was really distressing. I was in there for about 10 days. I had to be escorted to the courtyard to have a cigarette. It was often really hard to find an escort. They decided when I could have a cigarette. I don't think they understand how important it is to smoke when you feel stressed out.

After I left isolation, I had this case worker. I think she was a social worker – she was really young which I found insulting. And she kept telling me that my problem was that I was addicted to heroin. And if I stopped using, I would be OK. But they told me that I had post traumatic stress disorder and generalized anxiety disorder and depression and panic attacks. So it wasn't just the heroin that was making me mental. The heroin was helping me.

When I was in hospital I just wanted to get out. I had been in hospital 8 times that year for suicide attempts. I was mostly in for about 2 days. But then they kept me in, and wouldn't let me out. When I finally got out, I asked them if I could see a psychiatrist. And they said that I was not serious enough to be in the public system. So I tried to get a private one, but I needed a referral, but I couldn't get one. And even if I did get the referral, I wouldn't have had the money. It's lucky I found this GP. But I think I should have been discharged with a health plan. Not just kicked out on the street with no ongoing care. I needed to see a psychiatrist to work through my issues.

With the post traumatic stress disorder, it was a chance for me to say that I have this problem and to name the event that caused it. So it helped me to deal with the event that caused the disorder because obviously it was still causing me a lot of grief. Also, knowing that I really do have depression was helpful. Now when I am having a shit day, and feeling like shit, I know it's part of my illness. It helps me to handle it a bit more. So now when I feel like shit, I might try going for a walk to clear my head, or do some stuff to take my mind off it. Before I didn't know what was wrong with me and it was difficult to see any light. I didn't understand that I had a condition that was caused by this, and that there was something that I could do about it. It was just a big dark blur that never ended.

With my anxiety, I now take a tablet. Because my mental health issues have been so serious, my doctor is OK with me taking a tablet. If I have a panic attack, I take this tablet and within 20 minutes, I'm OK again. The tablet is addictive, but he says that is the least of my problems. He says that he doesn't care if I get addicted to these tablets because I'm already addicted to heroin. He thinks that it is better that I am a bit more sane. Other GPs won't even give me valium when I am anxious because they are addictive. I'm on heroin for fuck's sake – what's a valium going to do?

I think heroin is a life-time addiction. Even when you are not using, I'm pretty sure you are still addicted, or even thinking about it. A bit like a smoker – though it is 10 times worse than smoking and 10 times more addictive. I always need to smoke, whether or not I am using drugs. But heroin is more life destroying. Cigarettes are legal, that is the big difference. It is because heroin is illegal and the black market cost is so expensive that my life spiralled out of control. You have to commit a crime to get it and you have to go to dodgy places to get it.

Now I use heroin regularly. I work 5 days a week, and at the moment I manage a fairly normal life. I don't walk around asleep. A lot of people don't even know that I use drugs. I use about \$100 worth each time I use – my boyfriend and I get half a gram, and share it between us. It probably costs about the same as a night on the town – drinking and dinner.

Some overseas countries have been trialling legalising heroin. I'm not saying make it 100% legal, but people who are registered addicts – similar to a methadone program. Giving us a certain amount that is clean, so we don't get a dirty hit. And it would not be so expensive, which would cut the need for us to commit crime to pay for it. I know that addicts can get clean, but most addicts go back to it.

Kids always want to do things that they are told not to do. The thing I find annoying is drug education. They don't tell you the good things about taking drugs. They only tell you the bad things. When kids try heroin for the first time, they think "this is nice. This is not like they told me – it didn't make me fall over and lose all my teeth. I'm enjoying this, and I'm not addicted to it". And you're not the first time that you try it. So you have it again, and you are still not addicted. They think: "It's not like they say it is – I'm not in jail". So you have it a few more times, and then you are addicted.

It's not until you've been using it for a while, say a year, that you get to a point when you are really bad or skinny and all that sort of stuff. If the drug educators explained that there are people who enjoy heroin and there are good things about it. And they should stop telling people that they are going to be addicted after one hit – when you find that you are not addicted after your first hit, it creates a false sense of security. I was not addicted after my first hit, so I thought: "They didn't know what they were talking about" and it was not going to happen to me. So I had it a few more times.

I think they need to explain it properly – not this 'one hit and you're addicted for life'. They need to tell it how it is. Not just to scare people into not using – because kids are going to try it and see that it is not like they said it would be. If they told us the good and the bad, we could then make an informed decision. And if you do end up having it the once and trying it, you can then think that they did tell me it would be like this. And understand if I have it too many times, I may become addicted. So I'll be careful. People can say that they tried it, and tick it off their list of extreme sports to try in their lifetimes.

I reckon services would be better if they got people's families more involved in the process. Not the families they don't want involved – not the ones that they hate. My boyfriend and I have been together for 10 years – he is my family. When I went into hospital, they wouldn't tell him anything. He would try to visit me, and they would keep him away. They really should have sat down and talked with him about my problems, and what he could do at home to help. When I left hospital it was just me because my boyfriend did not have a clue what to do. If they had included him, it would have helped for after they discharged me.

The staff should think about what circumstances the patient is going back to. Is there family and friends? If so, how can we include them so that it is better for the person when they go back to their lives. Even with counselling, they should be thinking about your life with your family and friends. You can't be in counselling 24 hours a day – or you can't be at Birribi for the rest of your life – you are going to have to leave at some point and go back to your life with your family and friends and all the other things in your life. You have to have support in your life, not just when you are in counselling.

And there is another thing – I understand that psychiatrists have done lots of uni and they want to make a certain amount of money each year, but the government needs to step in and start subsidizing so that people can afford to access good people or to keep these people in the public system.

And it's not just about psychiatry – there are other things that can help us, but they are so expensive. Working with stuff that is your hobby. After you've been through a period of drug use or mental illness, you lose a sense of who you are and what you like doing and what your hobbies are. You haven't been doing those things because you have been so consumed by either the drug use or mental illness. So it's really important to find your sense of self, and what you are interested in, and it is really important for workers in both AOD and mental health to encourage you back into those areas. Or to find ways to get back in on your limited income – to find enjoyable ways to occupy your time.

Sometimes I think workers are too busy, and they don't have the time – it takes time to build up a relationship with someone so you can tell them things. And sometimes you just don't click with a worker, and you don't want to tell that person anything. I've had counsellors and workers who I just don't like and I don't tell them anything. I wouldn't tell them anything even if I was dying. They are just not someone with whom I can relate. There are some workers who I don't want – I'd rather have someone else. They need to understand this, and not continue to place me with that worker.

There have been times with services that are very frustrating because the workers kept changing. Like the time when I went onto a criminal court order. I had to go to the Justice Centre and see a worker there, who then got replaced, and then the next one got replaced too. During the same period, my AOD worker resigned and I got a new one, and they changed my mental health worker. Within 3 months, there were 6 different workers who I

had to tell my story to. I ended up asking if I could just write it and send it to the Herald Sun. How many times do I have to tell my story? I didn't mind doing it a couple of times, or there is some really good purpose for it. Like talking with you two. But having to bring 6 new people into my head was too much.

Also, with all the different agencies – AOD, mental health, housing, Centrelink – it becomes such a bureaucracy we have to deal with. There was a good period when my AOD worker was based at the same clinic as my GP. And my GP and AOD worker would talk with each other. So I was relieved that I did not have to repeat things. I gave them permission to discuss my case with each other. I would go to see my doctor, then straight after go to see her – one place, one morning. Not go here Tuesday morning, there Wednesday afternoon, there Thursday. Go to bloody Croydon this day. It becomes impossible trying to negotiate all these different people. And having to tell your story so many times becomes really draining.

My doctor gives me Xanax and it works really well for me. It has been one of the best things for me. And my counsellor tells me that I should not be taking it. My doctor has explained how addictive Xanax is, so I am well aware of how addictive it is. But it is the only thing that is working at the moment. I pick it up from the Chemist on a weekly pick up. I never have more than 7 tablets. My doctor manages it really well. So I get cross when the counsellors say that I shouldn't take it. They want me to just talk and work through my stuff, but that doesn't work. I take a pill for my panic attacks, and for my depression and anxiety. The pills work for me.

I also try to keep occupied – doing something that I enjoy – listening to a record or doing a drawing. Something to take my mind off how I am feeling. But it is hard when I don't have any money – when the electricity is off, I can't listen to a record, or even turn a light on to do a drawing, or watch the TV. I can't even get a library card because I accidentally forgot to return 10 books so I had a huge debt with the local library. So now I can't get a card so I can't borrow a book. There is no use explaining to them that I got evicted from my flat, and the landlord locked the place up, and the books were inside. It would have been nice if they understood that I can't return the books, and give me a break.

I feel that finding this GP was a break. I'm doing well – I've got a job which I've had for nearly a year. And my boyfriend and I will be opening a shop in a few weeks. So that is really exciting. It is such a big achievement for us both. I'm going to keep my job for a few months, to see how it all goes – so we have back up money, just in case. Until I know everything is safe – then I'll quit my job and work as his receptionist.

I always need to have a GP. I see my GP every 2 weeks, religiously. He's really good. I've been seeing him for the past 5 years and he knows everything that I've been through. And it's really constant, which is important. Unlike the other services that change workers frequently, he has been constant and reliable. Even if I don't need to get a script, I still go just to touch base with him. It is part of my routine.

I've also got a methadone doctor but I don't really like him. He disagrees with my GP about me taking Xanax because I'm a drug addict. So the methadone doctor, and the counsellor are on one side versus my GP. But this Xanax has been the only thing to stabilize me. While I've been on it, I've made so much improvement. My GP went away for a few weeks and I needed a script for my Xanax while he was away. But the other GP would not give it to me. So I'm very grateful for the relationship that I have with my GP. I know that it works, and I am happy. He sees it working and he is happy. I've even started to reduce my dose in the past few months, which is going OK. So I won't be on it forever, but at the moment it is helping and who cares what other people think. They don't understand the improvements that I have made. I'm now much more secure financially and I have bought things, and I am a bit happier. I now use drugs as my crutch a lot less.

I'm on methadone, and I am supposed to be clean, but I'm not. I use a hell of a lot less than I used to use. I now only use on a Friday and a Saturday compared to every day. And my doctor knows – not my methadone doctor but my GP who I see for my mental health. He is happy that I only use 2 days a week. He is not telling me that I have to get off it totally. He is not zero tolerance like some of the mental health people. He tells me that it is good that I am using only 2 days not every day. Unlike lots of others, he doesn't tell me that he is unhappy that I am using. Of course he says that it is not ideal, but it is a hell of a lot better than using every day." ❖

Appendix 3: Literature Review

A manual and computerised search using MEDLINE, PsychINFO, CINAHL, Cochrane Library and Sociological Abstracts databases and “Google Scholar” was undertaken. This literature search identified an extensive overseas literature on young people with a dual diagnosis, and an emerging literature in Australia.

This literature review is not intended to provide an extensive review of all the literature on young people with a dual diagnosis. Instead it is intended to translate some key articles for a generalist audience, including young people in our study.

The first part of the literature review draws heavily on an editorial by Drake and Wallach (2008). The second part of the literature review summarises a systematic literature review of treatment effectiveness for young people with a dual diagnosis (Bender, Springer and Kim 2006).

Previous research findings

Drake and Wallach (2008) describe several findings as now clear after nearly 30 years of research in this area. They state that people with mental illnesses such as schizophrenia, bipolar disorder, and chronic depression, use alcohol and other drugs at very high rates, typically two to five times higher than individuals in the general population (Kendler, Gallagher, Abelson, and Kessler, 1997; Regier et al., 1990). In addition, co-occurring substance misuse and mental illness is linked with adverse consequences of many kinds, including higher rates of suicide, HIV, hepatitis, homelessness, aggression, incarceration and fewer social supports or financial resources (Cleary et al. 2008; Green et al. 2007; Tsuang, Fong and Lesser 2006; Donald, Dower and Kavanagh 2005). Finally, people with a dual diagnosis have lower rates of treatment completion and higher rates of relapse (Warren, Stein and Grella 2007; Tyrer and Weaver 2004).

Framework for understanding types of treatments

The editorial by Drake and Wallach (2008) provides a convenient framework for understanding types of treatments that are available for people with a dual diagnosis. Drake and Wallach (2008) reviewed

four treatment paradigms that underpin current research: the neuroscience-pharmacology model (i.e. medical); the cognitive-behavioural model (i.e. psychological); the coercive treatment model; and the recovery-environment model (i.e. social). The following section summarises their arguments.

Neuroscience-pharmacology model

The neuroscience–pharmacology model suggests that medications that correct underlying neurocircuitry also address substance abuse or addiction. Drake and Wallach (2008) state that the evidence is not compelling. Medications that correct underlying biochemical imbalances in patients with schizophrenia, bipolar disorder, and depression have not been shown to have a consistent impact on substance abuse (Green et al., 2008; Frye & Salloum, 2006; Singh & Zarate, 2006; Nunes & Levin, 2004).

Cognitive-behavioural model

The largest study yet conducted of alcoholism psychotherapies was Project MATCH (1997). This study failed to show advantages for motivational enhancement therapy or cognitive behavioural treatment. According to Drake and Wallach (2008), the cognitive–behavioural model continues to be used with co-occurring substance use and mental health issues despite a lack of evidence of its effectiveness. In their systematic review, Drake and Wallach (2008) identified eight studies of individual counselling, largely based on motivational interviewing approaches. They claim that evidence for any impact on substance use was minimal and inconsistent.

Coercive treatment model

According to Drake and Wallach (2008), mental health policy in the US is driven by the public perception that individuals with serious mental illness, particularly those who also abuse substances, are dangerous and need to be monitored and controlled for the sake of public safety. This has resulted in public and political pressure for coercive treatments and intensive community monitoring. They cite a recent review of studies of forensic assertive community treatment teams

that found little effect on substance use (Morrissey, Meyer, and Cuddeback, 2007), while Drake et al.'s (2008) review of 4 legal intervention studies and 10 case management studies also found minimal or inconsistent evidence.

Recovery-environment model

The recovery-environment model is based on the premise that substance use, abuse, and dependence among people with serious mental disorders are largely initiated and sustained by environmental and social forces. This model argues that individuals with a dual diagnosis are “alienated from families, stigmatized in school and work settings, linked with deviant peer groups, housed with other unemployed individuals, shunted into impoverished and drug-infested neighbourhoods, and victimized by drug dealers and other predators in the inner city” (Drake and Wallach 2008, p191). A recovery community model involves decreasing environmental toxicity and increasing social and environmental protection and support for abstinence (Whitley, Harris, and Anglin, 2008; Whitley, Harris, & Drake, 2008; Whitley et al., 2008). Drake and Wallach (2008) state that the evidence for the recovery-environment model is “promising but incomplete”, largely because many of the commonly used approaches have not been studied (p191).

Effectiveness of interventions for young people with a dual diagnosis

This section of the literature review reports on a systematic review of treatment effectiveness for young people with a dual diagnosis (Bender, Springer and Kim 2006).

There were only six studies that met the selection criteria for this systematic review. Bender, Springer and Kim (2006) noted that this was a very small number from which to draw strong conclusions. They also noted that many of the studies had limitations. These limitations included predominantly male samples, questions about treatment adherence, small sample sizes, and high attrition rates. In addition, most studies involved participants' self-report. Although the standardised measures that were used were reliable and valid,

there is a possibility of measurement bias due to social desirability on the part of participants. Also, the research tools relied on retrospective recall and assumed accuracy in the participant memory of their behaviours, introducing another possible source of measurement error.

The section begins with a brief overview of the interventions for young people with a dual diagnosis that have been empirically tested and included in Bender, Springer, and Kim's (2006) systematic review. As with other systematic reviews, potentially effective interventions that have not been empirically tested with rigorous research methodologies were excluded in this review.

Multisystemic Therapy

Multisystemic therapy (MST) is a family and community based treatment approach that is theoretically grounded in a social–ecological framework (Bronfenbrenner, 1979) and family systems (Haley, 1976; Minuchin, 1974). The social-ecological model asserts that behaviour is determined by multiple forces (e.g. family, school, work, peers). MST is underpinned by the premise that a young person's antisocial behaviour is best addressed by “interfacing” with multiple systems, including the young person's family, peers, school, teachers, neighbours, and others (Brown, Borduin, & Henggeler, 2001). Thus, the MST practitioner works with not only the young person but also with various individuals that influence the adolescent's life.

Interactional Group Therapy

Interactional Group Therapy (IT) was initially developed by Yalom and later adapted for group work with adult alcoholics (Brown & Yalom, 1977). It utilises group dynamics and focuses on the importance of the clients' interpersonal relationships. Primary goals of IT include developing insights, enhancing self-esteem, and improving self-care and ultimately fostering more positive interpersonal relationships outside of treatment and decreased symptoms/problem behaviours. IT therapists aim to help clients develop trust, openness, and cohesiveness within

the group through open conversations about the group process and relationship issues in the group (Kadden et al. 2001).

Family Behaviour Therapy

Family Behavioural Therapy (FBT) seeks to decrease drug use and behavioural problems using a behavioural approach (Donohue and Azrin 2001). FBT therapists follow standard treatment components, including engagement, assessment, drug analysis, sharing of assessment and analysis with youth and family, and selection from a variety of interventions. Key to this treatment is allowing young people and his/her family to choose among interventions that will meet the diverse individual, familial, and cultural needs of the client.

Individual Cognitive Problem Solving

Individual Cognitive Problem Solving (ICPS) therapy employs empirically validated methods geared toward developing self-control and solving problems (Azrin et al. 2001). The treatment is based on the underlying principle that young people who lack constructive ways to address the environment have problematic behaviours. Problem-solving skills training attempts to decrease a young person's inappropriate behaviours by teaching the young person new skills for approaching situations that previously provoked negative behaviour. The focus is on a young person more than on her/his parents or the family unit.

Cognitive Behaviour Therapy

CBT views client behaviour, including substance-abuse and mental health symptoms, as maladaptive ways of coping with problems or of getting needs met (e.g. Reinecke, Dattilio and Freeman 2003). Cognitive therapy is founded upon two premises (1) that behaviour is adaptive and (2) there is an interaction between a person's thoughts, feelings, and behaviours. It follows then that clients' behaviours are learned and can be modified by changing thought patterns and using behaviour modification techniques.

Ecologically Based Family Therapy

Ecologically Based Family Therapy (EBFT) is based on crisis intervention theory (Kinney, Haapala, Booth, and Leavitt, 1990). This theory posits that people are most open to change during crisis. EBFT is based on a range of behavioural, cognitive, and environmental interventions catered to the young person and his/her family's needs.

Seeking Safety Therapy

Seeking Safety (SS) therapy is a form of psychotherapy designed to treat co-occurring Post Traumatic Stress Disorder (PTSD) and substance use disorder (SUD) through the development of coping skills across cognitive, behavioural, and interpersonal domains. Najavits (2002) describes five principles that guide SS, including (1) establishing safety as the first priority; (2) integrating treatment for PTSD and SUD; (3) focusing on ideals; (4) spanning cognitive, behavioural, interpersonal, and case management content; and (5) explicating therapist processes.

Randomised controlled intervention studies

For each of the six studies reviewed in Bender, Springer and Kim's (2006) systematic review, they asked the following questions:

- What is the evidence in support of the intervention being tested as an effective treatment for young people with a dual diagnosis?
- What degree of change is associated with the intervention?

MST compared to usual community services

Henggeler, Pickrel and Brondino (1999) examined the use of MST as compared to the usual community services in treating a sample of juvenile offenders, most of whom (72%) had a dual diagnosis. Usual community services included a variety of substance-abuse and mental health treatment in the community, including therapeutic groups, school-based, residential, and 12-step programs. Outcome measures included drug use, criminal activity, and days in out-of-

home placement. Findings indicate that MST reduced alcohol, marijuana, and other drug use, as well as the number of days youth spent in out-of-home placement. However, improvement was not maintained at 6-month follow-up.

IT compared to CBT

Kaminer et al. (1998) examined IT in comparison to CBT in a clinical trial with a follow-up study at 15 months post-treatment. The purpose of the study was to examine whether youth with externalizing versus internalizing co-morbid disorders could be matched by treatment. The sample included 32 adolescents between the ages of 13 and 18 who were leaving a partial hospitalization treatment program. Treatment attrition was 50% in the IT group and 50% in the CBT group, resulting in eight youth in each group. Both IT and CBT were provided over a 12-week period in weekly 90-min sessions. Outcome measures included objective and subjective measures of drug use as well as substance-related problems such as family functioning, academic function, peer social relationships, legal problems, and psychiatric severity. Findings indicate that CBT was more effective at reducing substance use than IT at 3 months post-treatment; however, both groups showed significant reduction in substance use at the 15-month follow-up.

FBT compared to ICPS

Azrin et al. (2001) compared FBT to ICPS in a clinical study that involved 56 youth, between the ages of 12 and 17, referred for treatment by detention staff, judges, probation officers, or school officials. Outcome measures included alcohol use, illicit drug use, satisfaction with drug use, overall mood, conduct, and school and work performance. Findings indicate that there was no difference in effectiveness between FBT and ICPS in reducing alcohol and illicit drug use and in improving conduct and mood. Significant improvements in both groups were observed from pre-test to post-test and were maintained at follow-up.

Cognitive behavioural therapy compared to psychoeducational therapy

Kaminer, Burlleson, and Goldberger (2002) examined the efficacy of CBT in comparison to PET for 88 predominantly dually diagnosed youth in outpatient treatment. Treatment attrition was 14% and did not differ between the two treatment groups. Outcome measures included objective (urinalysis) and subjective measures of alcohol and drug use as well as substance-related problems, including academic, family, peer, legal, and psychiatric problems. Findings indicate that CBT was associated with lower substance-use relapse rates than PET at 3 months post-treatment. However, this trend toward CBT did not last at 9-month follow-up at which time differential treatment effects disappeared and CBT and PET showed similar relapse rates. Thus, this study found CBT had better short-term treatment effects, but long-term effects were equally effective for the two treatment groups.

Ecologically Based Family Therapy compared to services as usual

Slesnick and Prestopnik (2005) examined the efficacy of EBFT as compared to services as usual in a runaway shelter. Outcome measures included drug use, psychological functioning (internalizing and externalizing), family functioning, and HIV risk variables. Findings indicate that the EBFT group had greater reduction in overall substance use than services as usual, but both groups showed significant and equal improvement in psychological functioning, family functioning, and HIV knowledge. Overall, reductions in high-risk behaviours were maintained through follow-up.

Seeking safety compared to services as usual

Najavits, Gallop, and Weiss (2006) examined the efficacy of SS in comparison to other services clients may attend, including Alcoholics Anonymous, pharmacological intervention, and other individual or group therapies. All participants (N = 33) were female and met Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) criteria for both PTSD and SUD.

Treatment attrition rates were not reported, but sample size decreased from intake (N = 18 for SS and 15 for TAU) to post-treatment (N = 14 for SS and 12 for control group) and further decreased at 3-month follow-up (N = 11 for SS and 9 for control group). Outcome measures included substance abuse, cognitions about substance use, and psychopathology. Findings indicate that SS participants had significantly better outcomes than participants in the control group, including improvements in substance use, cognitions related to SUD/PTSD, and several psychopathology subscales (anorexia, somatization). Only one measure of self-concept was more improved in control group than treatment group. The authors report that only some gains were maintained at follow-up, although with attrition, the power to detect significant relationships at follow-up was very low.

Recommendations for future research

Bender, Springer, and Kim (2006) recommend that future research should examine those interventions with evidence of significant change by comparing such interventions with a no-treatment control group. However, Bender, Springer and Kim (2006) do not refer to the ethical issues of having a no treatment group.

Bender, Springer, and Kim (2006) also recommend identifying subgroups of young people with specific psychiatric diagnosis and specific substance-use disorders, and evaluating treatments for these specific subgroups. ❖

Appendix 4: Bibliography

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Appendix 5: Interview schedule

1. What Alcohol and drug services have you used?
 - a. How long have you been attending (or did you attend) AOD services?
2. What mental health services have you used?
 - a. How long have you been attending (or did you attend) Mental Health services?

The first section of interview focuses on AOD services:

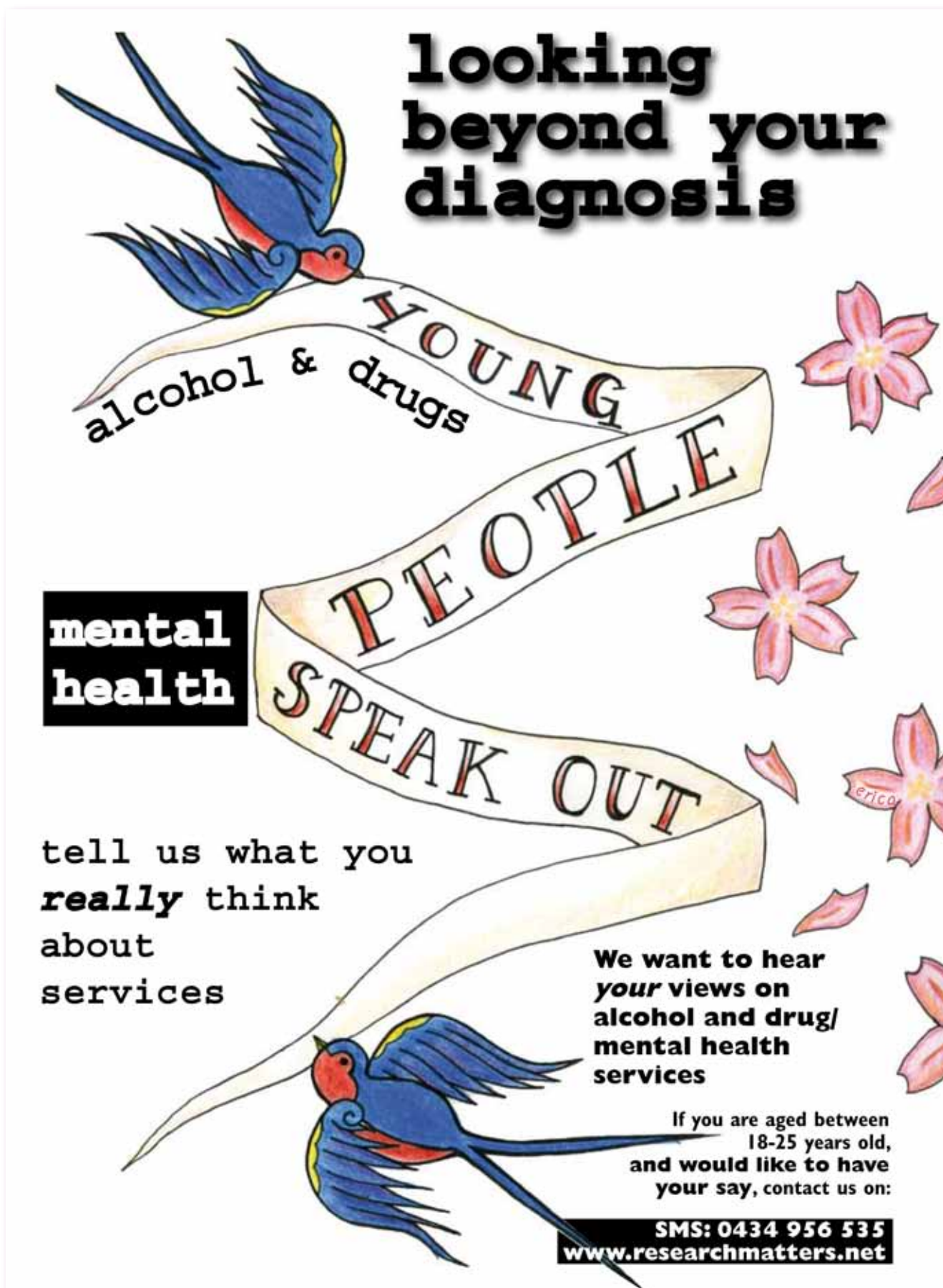
3. Describe some good experiences of AOD services.
 - a. Why was it good?
4. Describe some bad experiences of AOD services.
 - a. Why was it not good?
5. How would you make youth AOD services better – what are your ideas?

The second section of interview focuses on mental health services:

6. Describe some good experiences of mental health services
 - i. Why was it so good?
 - b. Describe some bad experiences of mental health services
 - i. Why was it not good?
7. What was the impact of being diagnosed?
 - a. How did you feel?
 - b. Is having a diagnosis a help (or a hindrance)?
8. How do you feel about taking medication?
9. What are your ideas about making mental health services better?
10. What are your ideas for making AOD and mental health services work better together?
11. Have there been moments when you felt “YES, that’s the help I needed from a service”. If so, please describe.
12. Have there been moments when you felt “NO, that’s not what I needed from a service”. If so, please describe.

This last section focuses on things that you do on a day-to-day basis to stay “on track”.

13. What types of things help you to stay well?
 - a. What type of things help you when you feel like shit?
14. What do you do when things start to go wrong for you?
 - a. What type of assistance do you need when things start to go wrong?



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beyond your
diagnosis**

alcohol & drugs

**mental
health**

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PEOPLE
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really think
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services

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