

# Access and equity project

Barriers and enablers associated with access and equity in alcohol and other drug treatment in NSW

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A study into the current barriers and enablers associated with access and equity in NGO alcohol and other drug treatment in NSW, commissioned by NADA, the Network of Alcohol and other Drugs Agencies, which is the peak organisation for the non-government alcohol and other drugs sector (AOD) in NSW. NADA is supported by funding from the NSW Ministry of Health.

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## EXECUTIVE SUMMARY

### Overview

This research project was undertaken to better understand the enablers to accessing Alcohol and Other Drug (AOD) services in NSW. Some of the main issues facing AOD treatment services is the reported difficulties that clients have in accessing treatment, sustaining engagement with treatment, and maintaining their positive outcomes in the post-treatment period. Using qualitative research strategies, interviews were conducted with 20 clients of AOD services and 15 sector stakeholders. All client-participants reported having been in treatment in the past and most (85%) had experienced three or more prior episodes of treatment. While they were recruited from a range of services, including crisis accommodation, day program, post-release support and residential rehabilitation, many tended to talk about their experiences at residential rehabilitation services. Client-participants included 13 men and 7 women. One participant identified as Aboriginal and one as LGBTQI. Stakeholder-participants worked in face-to-face service provision, but also in health promotion organisations, advocacy groups, peak bodies and youth services.

This report is organised around three key periods in the treatment experience: the period leading up to treatment and the factors that support clients to get there; the treatment period and the factors that help to sustain clients' engagement with treatment; and the post-treatment period and the factors that support the maintenance of positive treatment outcomes. Within this, we sought to explore how issues of access and equity impact each of these periods differently, in order to identify factors that maximise treatment outcomes for clients and ensure equity in such outcomes.

### Findings

#### What supports successful entry into treatment?

The key factors that were reported to improve experiences of treatment entry included: websites with detailed and accessible information that permitted the best opportunity for self-matching to treatment; short waiting lists and flexible, warm and welcoming intake procedures; families and other support people who could help navigate treatment entry or provide support while a client was on a waiting list; and having prior experience with the system and therefore the knowledge and skills needed to navigate re-entry.

Clients' capacities to access and make choices about treatment options were, of course, not equal. For example, pathways to treatment were easier for those with support networks where families and friends assisted with treatment entry or with support while on a waiting list. Moreover, prior experience in the treatment system helped clients to navigate subsequent entry attempts, suggesting that any positive engagement in the referral system, even if it does not result in treatment entry, is worthwhile. If this engagement is warm and welcoming, it can smooth that way for entry next time.

#### What supports clients to stay in treatment until completion?

At the basic level, some client-participants reported staying in treatment simply because treatment facilities offered a rudimentary safety that was not available to them in 'the outside world'.

However, many client-participants reported that they tended to stay at services where the 'culture' felt right. The service cultures that were valued were those in which staff and other clients were warm and accepting, where client self-determination was valued and supported, where supportive peer relationships were actively encouraged and seen to be part of the therapeutic journey, and where clean and comfortable physical surroundings were offered. These service elements were valued by clients because they made them feel that their lives and problems were important, that they were capable of having positive relationships with others, and that they were worthy of respect. Notably, however, supportive peer relationships were a therapeutic approach that could feel exclusionary to clients who were LGBTQI, Aboriginal or identified with another minority because they did not share the same histories and experiences. These clients reported feeling alienated and thereby missed out on the important therapeutic element provided through peer support.

Factors external to the service environment were also important in achieving treatment completion, including the quality of relationships with family and friends. For some client-participants, improving the quality of family and social life was a motivator to complete treatment, pointing to the way that treatment can be conceptualised as a shared journey with implications for a collective of people (family, partners, friends), rather than just as an individual endeavour.

#### **What helps to maintain positive outcomes after leaving treatment?**

Connection to self-help groups was commonly reported as a strategy for positive post-treatment outcomes and this was arranged by the treating service or set up by clients themselves. Formalised ongoing contact with staff at the treating service was also reported. In both approaches, setting up these arrangements early in treatment was seen to be important, as a way to ensure continuity of care into post-treatment and to maintain social connection with others, since lack of social connections was seen as a key driver of 'relapse'.

Having sufficient integration and collaboration across the service system was also viewed as important in order to ease clients' pathways into stable housing, mental health care and so forth. Clients found it difficult to address their needs for housing, mental health and other care because of the complexities of navigating service systems; although this inability of clients to navigate the system was sometimes seen as a deficiency on their part (e.g. some clients were viewed as 'too hard'), rather than as a problem with the set-up of services.

Finally, post treatment outcomes were seen to rest heavily on the individual skills that were acquired during the treatment period: self-care, goal-setting, self-motivation, and help-seeking. These skills were developed on the premise that they could be used by clients to manage their choices and decisions after they leave treatment. However, the focus on individual skill-building meant that 'relapse' could be construed as a failure in personal motivation, which can be experienced by clients as yet another example of their shortcomings, sometimes leading to them 'dropping off' contact with service providers who were often their only source of formal help and support. Overall, it seemed that participants had fewer opinions about best practice for the post treatment period than they did about successful approaches to treatment entry and retention.

## Conclusion

Our findings suggest that inequity is most pronounced in the early stages of the treatment journey, when clients are navigating referral pathways. While some clients had friends or family that organised and paid for their treatment entry, other clients got into treatment only through the intervention of police or because it was a court requirement. Inequity during treatment was less evident, although the focus on building supportive peer relationships in the treatment setting was experienced as exclusionary by some clients.

The impact of inequity in the post treatment period is less clear and this is because participants appeared to have fewer opinions about best practice in this period. Our observations suggest that the provision of post treatment care depended on the type and quality of the treatment service that the client was leaving, and that while some clients were connected to aftercare during their stay in treatment (this happens, for example, in residential rehabilitation), others received much less intervention and could exit treatment with very little support in place.

## Implications and recommendations

- **Consider ways to standardise the online presence of services in order to support self-referral and self-determination in service choice, and to improve treatment matching.**  
Online information is used by clients and others such as families, caseworkers, police, and social and health workers. Information should include policies on smoking, children, entry criteria, intake procedures, geographic location, rules and responsibilities while in treatment, room-sharing arrangements, aftercare arrangements and so forth.
- **Strengthen the role of people with lived experience in all aspects of the treatment journey, but especially in pre-treatment pathways and in the post-treatment period.**  
People with lived experience bring knowledge and skills with respect to navigating treatment entry, and giving care and support to other clients both during and after treatment. Peer support is a strengths-based approach that sends important messages to clients that they are capable of constructive relationships and contributing positively to the treatment journey of others.
- **Consider the range of ways to increase the size and contributions of the peer workforce.**  
Options to boost the contributions of people with lived experience are to strengthen consumer participation programs within treatment services, add outreach to these to support clients on their entry pathways, and to increase the range of models offering peer support in the post-treatment period. Other options should also be explored, including ensuring that peer perspectives are considered at decision-making and policy and practice levels, and keeping in mind the need for peers that reflect the diversity of identities and experiences of the AOD client group.
- **Increase the availability of AOD treatment places.**  
This will reduce inequities produced by long waiting lists whereby those with more financial and social resources can access immediate treatment or can be supported by family or friends during long waiting periods; but those without these supports are faced with waiting and accepting the

offer of any place that becomes available. Waiting lists create situations in which clients must 'play the game' and demonstrate sufficient motivation for treatment.

- **Treatment approaches that include families and support networks in a client's treatment journey will be more successful in achieving positive client outcomes.**  
Some clients view AOD treatment as a shared journey with collective implications (e.g. for family, partners, friends), rather than as an individual endeavour.
- **Increase the attention given to staff training and retention.**  
This is because the quality of the skills and approach of staff, including that they are warm, accepting and have high expectations, is one of the main factors in positive referral experiences and in keeping clients engaged during the treatment period.
- **Services should always consider the quality of the physical environment.**  
High quality physical surroundings send strengths-based messages to clients that they are worthy, valued and respected.
- **Services should consider whether the rules and regulations that they enforce are always necessary.**  
Overly regulated treatment environments are viewed negatively by clients and send a message to them that they are untrustworthy. Clients will not return to overly regulated services, if they have a choice.
- **Advocate for more research on the post treatment period.**  
Given the current scarcity of aftercare models, advocate for impact-focussed research so that new policy and practice in this area is evidence-based.
- **Continue the work to shift deficit assumptions of people with problematic substance use.**  
Views that people with problematic substance use lack motivation, self-control, and volition are damaging to clients. They impact staff-client interactions and, at a more structural level, shape perceptions what is possible in policy and practice interventions for people with problematic substance use. One way to shifting these assumptions is to enhance stigma-reduction interventions. Self-determination in treatment should be celebrated and supported wherever possible.
- **Individual skills-development is seen by participants as a key strategy in AOD treatment, but may contribute to clients blaming themselves for their post treatment 'relapse'.**  
This individual focus further entrenches views (held by clients and some staff) that clients are deficient and unable to be helped. Recognise the limits of overly individualised approaches and explore system level changes that will better support the broader social challenges that are part of clients' 'relapse' experiences.



## INTRODUCTION

One of the key compelling issues for those working in the alcohol and other drug (AOD) treatment sector concerns the reported difficulties that clients have in accessing treatment, sustaining their engagement with treatment, and maintaining their positive outcomes in the post-treatment period. This research, commissioned by NADA, was undertaken to better understand these issues and to offer insight about how support can be better provided to clients navigating the treatment system.

Existing research shows that trajectories of care can involve multiple periods of engagement, drop-out and re-engagement (Ashford, Brown, & Curtis, 2018; Brecht & Herbeck, 2014; Smyth et al., 2010; Manning et al, 2017). The research shows that a range of barriers exist that prevent treatment from being widely accessed in the first place, such as co-occurring mental health problems and other health-related complexities, lack of social support, and widespread stigma related to substance use (Treloar and Holt, 2006). Among individuals who do receive treatment, nearly two-thirds experience a recurrence of substance use within months after leaving treatment (Brecht & Herbeck, 2014) and those who experience 'early relapse' are likely to continue to have more difficulty maintaining their treatment goals (Charney, Zikos, & Gill, 2010, Hser, et al., 2015; Laudet, & Stanick, 2010; Orliková, 2018) compared to those who stay in treatment for at least six months who have been shown to have the most positive outcomes in the long term (Brecht & Herbeck, 2014; Hughes et al., 2004; Stone et al., 2018). This points to the importance of continued and structured care after leaving treatment (Bailey, Herman, & Stein 2013; Smyth et al., 2010), although the opportunities for 'aftercare' are limited in NSW. (See Appendix 1, page 43, for a detailed literature review.)

In this study, we organised our research questions and analysis around three key periods in the treatment experience: the period leading up to treatment and the factors that support clients take to get there; the treatment period itself and the factors that help to sustain clients' engagement with treatment; and the post-treatment period and the factors that support the maintenance of positive treatment outcomes over the long-term. Within this, we sought to explore how issues of access and equity impact each of these periods differently, in order to identify factors that maximise treatment outcomes for clients and ensure equity in such outcomes.

## STUDY AIMS AND METHODS

This study aimed to explore the barriers and enablers to navigating AOD services in NSW, as reported by clients of those services and other stakeholders. In doing so we sought to investigate:

1. Stakeholder and client perspectives about barriers and enablers to accessing services in NSW.
2. How these barriers and enablers differ across different treatment settings and locations, and for clients with differing needs and from different backgrounds.
3. Specific program elements and practices that maximise access and equity.
4. Organisational arrangements that maximise access and equity for clients.

It was envisaged that findings from this study would provide increased understanding of the barriers that may exist for clients in accessing or maintaining treatment and would also assist NADA in shaping advocacy and workforce capacity development opportunities to better support NADA members in their service delivery to communities in NSW. The study had ethics approval from UNSW ( HC190586), the Aboriginal Health and Medical Research Council of NSW (approval no. 1521/19) .

### Research design

To recruit client participants for the interviews, purposive sampling techniques were used to ensure diversity of experiences were captured in both metropolitan and regional areas of NSW. Recruitment sites were determined in consultation with NADA. Interviews were conducted face-to-face or video conferencing and lasted approximately 45 minutes to an hour. Similarly, stakeholders represented professionals from a range of service types and positions and included staff at treatment and other AOD programs, such as residential, community based, continuing care programs who work in various roles from management to front line work. These interviews were conducted over the phone. Clients who participated in an interview were remunerated with a \$30 voucher or \$30 cash depending on the service's preference to recognise the clients time and input to the research. Stakeholder participants were not provided any remuneration for their interview.

### Participant profile

#### Client-participants

Over the course of five months (November 2019-March 2020), researchers interviewed 20 clients and 15 professional stakeholders. Our initial research proposal was to recruit 25 clients, however COVID-19 related shutdowns in March 2020 meant that we were required to close recruitment. All clients were undergoing treatment at the time of the interview. The age range was 29-57 years but most were between 35-49. Many had extensive experience with problematic AOD use, since their teens, and had attempted treatment more than once. There were parents within this cohort, but most did not have their children in their care. Of those who did, one couple were trying to locate a long-term residential rehab setting that would accept children and the other was a single parent in residential treatment with her young child. The majority of clients were born in Australia, spoke English as their main language at home and identified as heterosexual. One participant identified as Aboriginal. See Table 1 for further information on demographic and participant details.

Table 1: Clients' socio-demographic characteristics

Socio-demographic characteristics	(N=20)	Percentage (%)
<b>Gender</b>		
Men	13	65
Women	7	35
<b>Number of times entered treatment</b>		
1-2 times	3	15
3 or more times	17	85
<b>Services</b>		
Dual diagnosis crisis accommodation service	5	25
Residential rehabilitation centre	5	25
Day program and aftercare service	9	45
Post-release support	1	5

### Stakeholder participants

Stakeholders had substantial work experience in the AOD sector and had worked or undertaken treatment across numerous organisations. Professionals were working across a very wide range of services including, dual diagnosis clinics, residential rehabs, community services, crisis accommodation, outreach, peak bodies, youth services and health promotion organisations. This report draws upon their perceptions and experiences of their current employment. In the case of client interviews, this report draws upon both their treatment episode, as well as experiences from their other interventions and services.

Table 2: Stakeholders demographic details

Socio-demographic characteristics	(N=15)	Percentage (%)
<b>Period of time in current position</b>		
0-2 years	1	6.7%
2 years or more	14	93.3%
<b>Positions held</b>		
Front line worker	7	46.7%
Managers, senior managers and directors	8	53.3%

### Data analysis

The thematic analysis process involves researchers closely reading the transcripts and noting recurring ideas both explicit and implicit (Braun and Clarke, 2014). This stage of the analysis, known as open coding, is followed by several iterations of 'axial' coding (refining the set of initial codes) (Ezzy, 2002). Three team members were involved in the thematic analysis. Joanne Bryant, Rebecca Gray and Lise Lafferty met on several occasions to discuss the coding frame. The refining process involves the researchers discussing and comparing the coding and reaching a consensus as to which codes are most relevant to the research at hand.

The themes were developed using a socio-ecological framework which identified individual-level, social-level (i.e. social networks, families, friends, peers others) and structural level (e.g. funding arrangements, organisation of services) enablers. Staff and client data were analysed and presented

together. The analysis, guided by the research questions, focused on factors relevant to before (gaining treatment access), during (staying in treatment until end of program), and after treatment (maintaining outcomes after treatment completion). Rebecca Gray coded the data and drafted two sets of summaries, using this approach. One summary was an in-depth 25-page description of data themes, and the second summary was a three-page overview of themes. Final themes were refined by Joanne Bryant through the writing process, and have been presented according to those which appeared most dominant and also held most relevance to the overarching aims of the project. Analysis was also guided by the Literature Review (Appendix 1) which was first-authored by Robyn Horwitz. Analytic summary documents were rewritten, recommendations were developed and refined, and these are presented in this report.

## FINDINGS

### What supports successful entry into treatment?

Clients and staff identified a number of key supporting factors that helped their entry into treatment. These included, at the initial stages, the presence of high-quality, detailed and up-to-date websites, and short, flexible, welcoming intake interviews. Clients' capacities to access and make choices about treatment options were, of course, not equal: those with more social and material resources (such as family support, more financial security, a home) had more choice. Similarly, those with prior experience in the AOD treatment system possessed more effective knowledge and skills in navigating entry pathways, than did those who were new to treatment systems.

#### High quality online presence

Services seem to be able to improve their accessibility, at the initial phase, with clear and up to date webpages. Having a robust online presence enabled clients to make choices about services that best suited their preferences and life contexts, and supported clients' self-determination in treatment choice something that is noted as a key supporting principle of equitable systems design (Rush and Urbanovski, 2019). Online information was also supported through networks and word of mouth recommendations which enabled individuals to make choices about their AOD treatment. However, importantly and as will be described later, making 'choices' about treatment services was the privilege of those with more social and material resources, and of those with prior experience and skill in navigating treatment access.

Services with a clear and up-to-date online presence were valued because they enabled clients to explore their preferences about geographic location (metropolitan versus regional setting), program models (for example, abstinence versus harm reduction or services that permit clients to bring children), and quality of accommodation (for example, needing to share a room with other clients or having outdoor spaces). Some clients placed high importance on selecting services that suited their needs and preferences. Henry (male, dual diagnosis client) said, "I've always looked online and got numbers myself and rang them myself." Indeed, most participants (or their relatives) found their preferred service by "googling". One of the key features that clients looked for in a service related to the level of regulation that services imposed on clients, a popular one being rules about tobacco smoking:

Well they are all pretty easy to get into I suppose, but you just got to ... different rehabs have different programs [...] and you can smoke up there, so before I was ringing around for other places, you couldn't smoke. (Jude, client, dual diagnosis service)

Client-participants seemed to avoid services with no smoking policies or those that were perceived as overly regulated. The extensive rules and regulations of some services were seen to be problematic by many clients, although this did not mean that clients thought services should not be structured. In fact, lack of clarity and communication of rules and regulations within treatment services, particularly residential services are common complaints (Bryant, 2018; Lubman et al., 2014). Clients valued the opportunities provided through routines and rules and some viewed this as

part of their treatment: “Kind of having it regimented and you know not used to living in such a regimented way” Henry (client, dual diagnosis service). However, too many rules, especially those that were viewed to be unrelated to their treatment, were viewed as unnecessary and sometimes patronising. This supports previous findings that clients appreciate the high expectations that services have for their behaviour and treatment progress, and value rules and regulations as therapeutically necessary, as long as they are fairly applied to them and others (Bryant, 2018).

Maximising clients opportunities to learn about their treatment options – through pre-entry online ‘googling’ – maximises their knowledge about treatment, helps to build realistic expectation about what treatment will be like and assists with their personal assessments about what they think they can tolerate (for example, whether they can go without smoking). In this way, increasing and standardising the online presence of treatment services works to increase clients’ self-determination by supporting them to choose a service and treatment model that best aligns with their preferences and circumstances. Increasing the opportunity for clients to make choices about their treatment works from the strengths-based assumption that clients possess the capacity to make responsible choices for themselves. This is important because it disrupts popular beliefs that people with substance use problems are without volition and necessarily compulsive and in need of help (Karasaki et al, 2014). However, while it is important to maximise the opportunities for clients to make choices about their treatment, such ‘choice-making’ is not equally available to all and measures must be considered in order to better support treatment entry for those with fewer resources and skills.

High quality intake procedures: skilled, flexible, welcoming

Services with short waiting periods were valued by participants, as were flexible and welcoming intake procedures. Positive entry experiences were described with responses like “it was very quick” (Henry, client, dual diagnosis service) and it was “pretty straightforward” (Suzie, client, residential rehab service). Once the initial phone conversation and referral was complete, participants described positive experiences of welcoming and lengthy intake interviews which enabled them to understand the program in greater detail, and to ask questions:

[I had] an over the phone interview just to get sort of like the basic idea of what and how ... yeah, what was wrong with me [laughs]. I’m trying to think of a better way of saying it, but yeah, about the amount I drink and my support at home and things like that, so I think they can tell if like they can help me or not and then yeah, but apart from that, it was all pretty straightforward (Jeannine, client, residential rehab)

Sonja (stakeholder, senior manager) noted the importance of professional skills in ensuring high quality intake processes and her comments, below, echo those of other participants who provided interviews for this study:

[First] describe the nature of the service, so people can be a lot more informed about whether this is the right place for them, there should also be a greater emphasis on the skills of an intake worker or the person who’s doing the initial assessment, because what frequently happens is that a client is assessed by someone who might not necessarily have the skills or the time to really engage that person to work out whether indeed this is the

right fit for them, so you know, an improved system would perhaps have a greater emphasis on engaging clients and supporting them if perhaps there is a waiting list, so there's a lot more emphasis keeping people engaged and giving them what they need prior, if indeed there is a waiting list, rather than putting the onus on the client to sort of engage themselves. (Sonja, stakeholder, senior manager)

This finding supports existing literature that cites the barriers to treatment access to be factors like long wait times for appointments, lack of trust of institutions, and inability to follow through with the treatment plan (Priester et al., 2016). There are also service-level barriers like the 'organizational red tape' involved in treatment enrolment including the need for official identification, medical plans, prioritisation processes (Appel et al., 2004, Lubman et al, 2014), and the lack of pre-treatment support to engage clients while they wait for intake places (Johnson et al., 2015).

Access to treatment on release from prison is also critical for people with problematic alcohol and drug use as there are many triggers for women relapsing to substance use when re-entering the community (NADA, 2013) including problematic relationships, exploitation, lack of social support, and limited resources for addressing these and other challenges (Johnson et al., 2015). Skilled workers can better identify clients who require more support in the entry process. However, beyond matters of individual worker skill, Marcia (stakeholder, senior manager) identified how services can better structure their entry pathways in order to better accommodate clients, making them less rigid and more flexible:

I think [services] that have too many barriers or too many kind of rules, so I think where like for residential rehabs where people have to contact them, you know a certain time every week or a certain number of times, can be a real barrier for some clients. So I think being more flexible, allowing your worker to call on the client's behalf if they have a support worker, because if the person is homeless or not having a phone with them or whatever, so I think kind of be more flexible around that intake procedures and again, about just kind of giving as much information and detail about what the program will look like to kind of reduce the barrier of people going, but they are not staying at treatment because they kind of weren't aware of what it really was going to be like. (Marcia, stakeholder, senior manager)

Rigid procedures, such as those that require clients to contact a service regularly while waiting for a place, were difficult for many clients, especially those who were more vulnerable and had less support. The welcoming quality of the intake process was also seen to matter significantly. For example, Karl (stakeholder, frontline worker) viewed person-centred approaches as central in this process:

If it's like, you know, an interrogation, so clients really don't like giving away too much information and as I said, the intake process at a lot of places ask you everything, that you're meant to kind of, yeah, discuss everything about your life and a lot of the clients just don't feel comfortable doing that anyway, let alone first off with a complete stranger. So, in places, I think the best results have always been with officers that are just very, very person centred, that actually explain to the client like what exactly is going on and, you know, kind of like what you said to me in the beginning, you can drop out if you don't feel comfortable or let me know, and just be a lot more reassuring in your language rather than just getting stuck into the work. (Karl, stakeholder, frontline worker)

In sum, the best intake procedures were seen to be those that put less onus on clients by paying attention to their needs and life circumstances, skilfully and accurately collecting information from clients, and delivering this through a warm and welcoming manner. Indeed, intake was seen as an opportunity to set clients up for the best outcomes during treatment by establishing respectful relationships and maximising opportunities to inform clients about the treatment experience – what it’s going to be like and what to expect. Such work was best done by skilled and experienced staff.

#### Demonstrating ‘readiness’ and ‘motivation’

Many professional participants talked about the lack of adequate funding for treatment places in NSW. This was seen to create a flow-on effect whereby clients needed to compete for treatment places, something that has also been found in earlier research (Ashford, Brown & Curtis, 2018; Hunt et al., 2017; Priester et al., 2016). Sonja (stakeholder, senior manager) describes:

Firstly, because of the scarcity of resources, so funding itself of places in treatment that don’t actually meet the needs of the amount of people who want access to treatment has created a bit of a system whereby there’s a real emphasis on people needing to demonstrate their readiness or their motivation to enter treatment, so over time, that’s really been often used against people a bit, in that they need to ring at certain times, they are on long waiting lists and you can appreciate that when people are ready to do something about their substance use, you sort of have to catch them in that moment. (Sonja, stakeholder, senior manager)

Sonja describes how a shortage of treatment places means that services are perceived to have adopted triage approaches, in which those clients who are seen to be more ‘motivated’ and ‘ready’ are more likely to be given places. Such dynamics present significant problems for clients who appear ambivalent, or are assumed to be less motivated as might happen with clients who are attending due to diversion arrangements. Those who have fewer skills in navigating the AOD treatment system, such as those who are new to the treatment system, may also be disadvantaged in this context if they do not know the need to *appear motivated* and ‘ready’ for change. In any circumstance, assumptions about the motivation of clients should be avoided as even those clients who are truly ambivalent should be given the right to attend, as often ‘ambivalence’ might disappear once a person is immersed in treatment.

#### Social and material resources: families, friends, safe housing smooth the way

Clients arrive at treatment with different resources and these significantly shape their entry pathways to treatment. The ‘choices’ described by clients in the previous section are much more available to some clients compared to others. Some people negotiate treatment access while in crisis – chronic homelessness, significant health issues and with no family or friends to support them – while others gain entry because they have families that pay for their treatments and can give them a safe place to stay while waiting for a place. Moreover, some people have had multiple prior experiences of gaining access to treatment and this gives them knowledge and skills that those new to the system lack. Service systems have a role in ameliorating this inequity by doing more to support those in crisis and those new to treatment systems



### *Housing and incarceration*

Entry pathways were significantly shaped by the housing conditions in which participants lived prior to their entering treatment. The stability and quality of accommodation affected people's ability to access treatment, with people living in unstable or poor-quality accommodation reporting adverse effects on their general wellbeing, their ability to access treatment, and their mental health status (Treloar & Holt, 2008). Those who had been homeless were relying on police referrals or awaiting housing before starting long-term treatment, and those with housing seem to find it easier to source their preferred treatment program. Efforts to address homelessness among people with alcohol and drug problems is essential to ensure uptake of treatment (Lubman, Manning & Cheetham, 2017; Sun, 2012; Wittman, Polcin & Sheridan, 2017). For homeless clients, motivations to undertake treatment were markedly different to those with housing: they were influenced by a need to be safely housed, to protect their declining health, and for some to simply avoid overdose and death. Suzie described this with lucidity:

[My relative] called me up and told me, "you've got to get to the doctor and you've got to get a referral because you can't do this anymore!" [...] I was unable to make any sort of decisions, so I just ... like I knew that my kidneys had started aching, like everything was just in decline and I knew that if I didn't get the referral, I was going to be dead soon, I just felt my body disintegrating [,,,] she was right when I got here and I was like, "you picked the right one". (Suzie, client, residential rehab service)

Kambala (client, dual diagnosis service) described a similar situation where she depended on police to know where to refer her. Her experience is far from those described earlier by clients who undertook google research to find a service that best meets their needs:

It's really scary and I never want it to happen again, and when I fell through all the loopholes, you know, you've got like ... say the police telling you they don't know where they're supposed to take you and you can't even call home, there's nothing there. You do feel like sometimes a lot of people are not actually given the information they need. (Kambala, client, dual diagnosis service)

Clients who had experienced periods of incarceration seemed to be highly motivated to initiate treatment, to avoid future periods of jail. They found, however, that access to AOD treatment was not straightforward. Gianni felt compelled to seek out treatment to help him avoid a return to drug-related crime, and the cycle of incarceration he felt he was in: "Yeah I was like, 'wow, I don't want this life', yeah time to change."

Participants with significant social marginalisation tended to report on particular kinds of substance using histories, often involving drugs that were seen to be more 'hard core', like ice or heroin, and histories of injecting drug use. This tended to further obstruct their access to treatment due to the stigma attached to their particular form of addiction and the assumptions that service providers hold about people who use 'hard drugs', as described by Jewel (stakeholder, front line worker):

I think there's a lot of stigma around certain drugs, is what I've found in the [regional and remote areas]. So, for example, if someone's suffering with alcohol abuse, a lot easier to get treatment for. If someone's been addicted to ice and showing some of the, I guess, negative behaviours that can come with being under the influence of ice, it can be harder to get people treatment unfortunately (Jewel, stakeholder, front line worker).

These findings support current literature that shows low treatment seeking among methamphetamine users with the poor orientation of services to this group, lack of information about treatment options and little confidence in the effectiveness of these programs as reported barriers to access (Cumming et al., 2016; Kenny et al., 2014; MacMaster, 2013). In addition, literature highlights the perception of negative staff attitudes towards methamphetamine-using clients as a barrier by methamphetamine users (Kenny et al., 2011; Woodall and Boeri, 2014).

Those with significant marginalisation were often in dire situations when trying to navigate their way into treatment and this essentially removed any scope for the 'choice-making' described by other participants who used google to find their best service match. Instead, participants in crisis depended on the goodwill of relatives or, in the worst cases, police to assist with their entry to treatment. Despite these challenges, this cohort expressed high motivation to undertake treatment – they wanted to be treated - and were dismayed that gaining access was so difficult. They tended to make sense of this as “their problem” or “their situation” rather than as a problem with the treatment system and the unequal opportunities it offers.

#### *Social resources – family, friends, acquaintances*

Participants with family connections were more likely to access treatment via a family GP and some were able to undertake their waiting period within the family home. Families also provided support with help-seeking and recommendations of “quality” services. In some cases, parents negotiated entry on behalf of their children and paid the admission fees:

Mum helped a lot, to be honest... while I was in rehab. It seemed to go pretty smooth because mum was cluey enough to find this place during my first week in rehab. So, by the time it was time for me to leave, yeah, they were just ready to take me. It wasn't complicated. They didn't say, “Come back another day.” They just ... it was very smooth, just brought in my suitcase, said, “Hey, I'm Dougal” and straight into my room, yeah. (Dougal, client, day program setting)

Friend and acquaintance networks could play a similar role, for example Jude used his network to access crisis services:

There's a guy (name), he knew me back from when I was at (another location) with my ex-girlfriend. I rang him up and he remembered my name from then and when I rang up and asked him for rent ... I was in this place and boarding house and I needed some help with some rent and then this guy who was here, I can't think of his last name, but he said “come here” and I said I'd never heard of the place, so I said “yeah” and then I've been here ever since. (Jude, client, dual diagnosis service)

Those who had social connections were more able to access treatment and wait for their place. Friendship networks could offer 'inside knowledge' and families could offer a safe place to stay and financial support. Those without these supports faced more difficulty in gaining access to treatment places.

This points to some ways in which services can play a stronger role for those without families: for example, provide them with support in navigating treatment options, finding them a place to stay during waiting period, and by lending or waiving admission fees. Professional participants described the range of ways that such support could be formalised by prioritising clients who lack resources and social support. For example, Karl described a tiered wait list system that could fast track clients that were more vulnerable, as long as there was GP support. Vulnerable clients included Aboriginal people or pregnant women who were seen to be at greater risk of detrimental health outcomes.

#### *Financial resources – private health cover*

Some clients described how their entry into treatment was gained because their family members paid for their treatments and could give them a safe place to stay while waiting for a place. Their experiences were in marked contrast to those who were homeless and in crisis. Some clients like Gareth (day program service) and Jeannine (residential rehab) had financial resources such as private health cover which meant they had priority access to treatment places:

I guess the good thing about them is you can get in there straight away, so when I start drinking, I can recognise the signs, I can break the cycle straight away. (Jeannine, client, residential rehab)

Clients with more financial resource had greater access to AOD treatment, although these clients felt that treatment at private facilities was often not as good as what was available in public services because the treatment periods at private facilities were shorter and the quality of staff was perceived to be poorer. However, the stories of clients with private cover demonstrate the inequity in which treatment places are gained whereby those who can pay can 'break the cycle' immediately and begin their treatment journey.

#### *Prior experience -knowledge of the system smooths the way*

Having previous experience with services, from prior treatment episodes, was identified as something that improved clients' ability to access treatment in future treatment episodes. They knew better the sort of treatment models and settings they preferred, for example, services with access to outdoor spaces, that were 'less regimented' (Henry, client, dual diagnosis service) and permitted smoking (Jude, client, dual diagnosis service). They also had increased skills to navigate reception staff, such as, knowing that they need to demonstrate 'readiness', undergo intake procedures and what was required to manage wait lists. This learned knowledge smoothed the way into treatment for these clients and suggests that support could be provided for those with less experience. That is, services might improve referral pathways for those new to the system, perhaps by leveraging interagency relationships to help identify treatment novices, provide them with information and to connect them with support. Support from people with lived experience of addiction seems particularly valuable in helping to navigate treatment entry because the knowledge

and skills required to gain entry is tacit – needing to appear ‘motivated’, knowing what counts as ‘readiness’, understanding the impacts of not being able to smoke, and so forth. Advocacy organisations could provide such support or, relatedly, existing consumer participation activities within, treatment services, could be expanded to include outreach to incoming clients.

### Summary and implications

In telling us about their best experiences of accessing treatment, participants identified a series of important enablers: websites with detailed and up-to-date information that permitted the best opportunity for self-matching to treatment; flexible and welcoming intake procedures; families and other people who could help navigate treatment entry or provide support while on a wait list; and having the knowledge and skills to ‘play the game’ required to gain entry to treatment.

Below we discuss some implications of these findings.

Successful enablers were those that were underpinned by a recognition of clients’ capacity for choice and self-determination and a view that clients are best placed to match themselves to treatment. **Increasing clients’ self-determination in choosing treatment** could be supported through more systematic and centralised websites which could be used by clients themselves, but also families, police, caseworkers and other social service workers. **Centralised websites** can streamline and speed up pathways into treatment. For example, Victoria Police use a system called ‘Supportlink’ (more recently renamed ‘Victorian Police e-Referral’) which is an online e-referral system used by police to connect individuals to social and health services. Partnerships are established with local agencies and tertiary-qualified referral co-ordinators triage requests to the appropriate agencies (Green et al, 2015). There is also a role for advocacy in supporting clients to navigate the referral system. This could happen through the expansion of the existing consumer participation activities at treatment services, perhaps by adding an outreach element. Here specialist peer workers could have specific roles to advocate for and navigate treatment entry on behalf of clients. The Pharmacotherapy, Advocacy, Mediation and Support’ (PAMS) Service in Victoria is an example of a service whose scope of work is close to what might be needed – they support clients to navigate and resolve issues that arise during pharmacotherapy treatment. With appropriate financial and training support, this sort of advocacy work could be expanded to assist clients to navigate entry into treatment. Currently there is no equivalent organisation in NSW.

Families, friends and others often assisted with treatment entry, based on their research and knowledge about the treatment options available. Given this informal ‘word of mouth’ referral system, there is scope to **increase the reputation of some services**, their treatment approaches and models and the reasoning behind their ‘rules and regulations’. One way for services to address this is to undertake ongoing evaluation activities that engage strongly with client feedback.

Pathways to treatment were easier for those with more resources – a home, supportive families, knowledge of the system. Clients with more complex needs - in particular those who were homeless or caught up in the criminal justice system – required a more **holistic response that attends to the diversity of needs, experiences and identities**.

The knowledge and skills needed to more successfully navigate treatment entry were often gained through prior experience. This suggests that ***any positive engagement in the referral system, even if it does not result in treatment is worthwhile***. If this engagement is warm and welcoming, it can smooth that way for entry next time.

The entry points reported to us by participants included via the criminal justice system (e.g required by the court or actively chosen by a client as a way of reducing the likelihood of recidivism), police, caseworkers, family members, partners, General Practitioners and self-presentation. This signals that a ***range of entry points exist*** and that 'case detection' works (at least for some) across the system. This 'case detection' capacity could be improved by further increasing the level of collaboration between agencies, perhaps through strengthening existing interagency networks. Relatedly, strategies could be implemented to improve non-AOD workers confidence and knowledge about therapeutic options to increase their opportunities to refer and to maximise 'treatment matching'.

Finally, ***waiting lists*** were implicated in several of the research themes reported above. The presence of long waiting lists produced a range of inequities: some clients could access treatment immediately if they had appropriate private health insurance; other clients had families or friends who could support them during the waiting period with housing or finances, and others had no such resources were faced with waiting it out in their current circumstances and accepting the offer of any place that became available. Waiting periods created situations whereby clients needed to 'play the game' by demonstrating sufficient motivation for treatment, and required other support services (that were themselves already stretched) to step in with support to help clients through until a treatment place arose. This speaks directly to ***a structural problem of insufficient treatment places***. Increasing the availability of treatment services will directly impact inequities in AOD treatment uptake.

#### Recommendations for increasing equity for those entering treatment

- Consider ways to standardise service website content in order to support self-referral and self-determination in service choice, and to improve treatment matching. This information is used by clients themselves, and others (families, caseworkers, police, other social and health workers). Information should include policy on smoking, children, entry criteria, intake procedures, geographic location, rules and responsibilities while in treatment, room-sharing arrangements, aftercare arrangements and so forth.
- Strengthen the role of advocacy organisations and consumer participation programs in the treatment referral pathway. People with lived experience have extensive knowledge and skills in navigating entry and, as this report identifies, they play a key role in treatment retention and post-treatment experiences because of the value of shared experiences.
- Look at ways to further strengthen interagency relationships, including ways to build the knowledge and confidence of non-AOD workers about treatment options. This can increase the opportunities for non-AOD workers to refer and support 'case detection'.
- Continue the work to shift deficit assumptions of people with problematic substance use – for example, that they lack motivation to be treated. Self-determination in treatment should be celebrated and supported wherever possible.

- Increase the availability of AOD treatment places. This will reduce inequities whereby those with more financial and social resources have more choices, can access immediate treatment or can be supported by family or friends during long waiting periods; but those without these supports are faced with waiting and accepting the offer of any place that becomes available.

## What supports clients to stay in treatment until program completion?

Participants identified several enabling factors that supported clients' retention in treatment. These included service cultures in which staff were warm and welcoming and which recognised the value of supportive client-client relationships and actively encouraged these; service cultures that supported client self-determination; physical environments that were clean and comfortable; and the presence of family and friend support networks that acted as motivation for a 'better life'. Although for some clients, staying in treatment simply provided more safety than returning to 'the outside world', as described next.

### A safer place to be

For participants who were in crisis upon entering treatment, motivation to stay until program completion were often driven by basic needs for a safe place to live. These participants were leaving situations of great risk - rapidly declining health, homelessness, violence – and residential treatment services provided a 'safe space'.

I guess it's just a safe space, it's certainly not ideal, you don't want to be here, you certainly don't want to be here for any other reason than you need to be. (Jude, client, dual diagnosis service)

They give you a safe space in these four walls, in the confinements of these four walls really is you know ... you are not on the streets, you're not falling asleep in a laneway, you are not getting kicked in the head while you are asleep in the laneway, so you know, you've got a bed, you've got some safety, you've got some food here (Henry, client, dual diagnosis service)

I needed somewhere safe too. I was assaulted when I was on the street ... and I needed somewhere I could feel safe to start the healing process and that here has been that. (Ruth, client, day program service)

The need for safety – particularly housing - was a key motivator for staying in treatment. This was seen to boost client-participants' willingness to continue even if they did not particularly enjoy being in treatment, as Jude (client, dual diagnosis service) pointed out "it's certainly not ideal, you don't want to be here." For some participants, life prior to entering treatment was dire and their motivations to stay were not related to any features of the service itself, but rather to the fact that it is not "the outside world." (Bobby, client, dual diagnosis service)

### A staff culture that is warm, welcoming and safe

Consistent with findings about the value of a welcoming intake process, participants talked about how this culture was also central to keeping them in treatment over the long term. A culture of warmth and acceptance was seen to send a clear message to clients that they were important, valued and that their lives and problems mattered. Clients talked at length about the value of feeling welcome. They often described the importance of this through stories about when this warmth was absent, and when they felt belittled, ashamed and unsafe. Ruth (client, day program setting) told us about one of her experiences:

I got the same doctor when I was taken up to the ward and he was actually quite obnoxious and had no understanding. He treated me dreadfully, you know he obviously had quite an ignorant opinion and just saw me as trouble and he said to me on one point, on the second time I was admitted there, so he said, “you make a bloody habit of this then”. (Ruth, client, day program setting)

Such experiences are damaging not only because they deter people from staying in treatment and from taking up further treatment, but also because they further entrench deficit views of self that many people with substance use possess. Ruth went on to tell us how staff, those who are ‘non-judgemental, understanding, have empathy’, made the difference for her:

And then the staff. I mean, they go above and beyond, they’re beautiful, they are remarkable human beings. What they do for people and who they are for people. You know it’s ... when you find yourself homeless, traumatised, you’ve got addiction problems, to be supported by people who are non-judgmental, understanding, they have empathy, know where you are at in your life, I mean you can’t put a price on that. It really makes a difference. (Ruth, client, day program setting)

This warm and welcoming culture plays a critical role: it lays the groundwork for maximising therapeutic impact. Feeling safe fosters a climate that was optimal for treatment outcomes and supporting clients to “heal” or better manage their AOD use.

Professional participants knew the value of this warm and welcoming culture, and by consequence were worried about maintaining quality and motivation among staff, and spoke about the need to reduce staff turnover. When staff-client relationships are central to treatment completion and outcomes, staff motivation and retention is crucial. Professionals perceived administrative burden and time poverty as hindering their working alliance with new clients. For example, Karl (stakeholder, frontline worker) described some of the challenges for services:

It’s like nearly every service I know, there’s just not enough staff to manage everything, and when you talk about health, there’s a lot of policies and procedures when I used to work there that you have to go through no matter what, actually that could provide a barrier as well because a lot of paperwork needs to be done to make sure that it looks like, you know, the best care is being given to the clients, but a lot of times, the clients don’t want that and they would disconnect. (Karl, stakeholder, frontline worker)

Increased experiential training (regarding shame and trauma) and the use of evidence-based practice has been shown in other research to improve relationships between client and service providers and enable the shift required for the client to experience positive treatment outcomes (Green et al., 2015; Hanson & Lang, 2014; Oral et al., 2015). Trauma-informed care not only realises the widespread impact of trauma and understands potential paths for recovery but also helps staff to recognise the signs and symptoms of trauma in clients and families (SAMSHA, 2018). Staff training in identifying needs beyond clinical symptoms is considered important because it permits staff to respond with a wide range of behavioural and other supports and in turn maintain client engagement in treatment (Savic et al., 2017).



## A culture that encourages supportive relationships between clients

Many clients talked about the value of the ‘lovely people’ that they formed relationships with during treatment and how these relationships lifted them during times of doubt or when facing challenges. Such relationships supported them to continue with their treatment. Kambala, who was interviewed at a residential rehab, described this as ‘healing together’:

It’s to be able to heal together, as individuals, like separately but in an environment where we’re together and I suppose it’s like to be able to enjoy the process of recovery with the ability to be able to start living now and moving forward with studies and with life, yeah. (Kambala, client, dual diagnosis service)

Jeannine described how the value of peer client-client relationships was that there were other people who ‘understand what you’re going through’. This shared experience is powerful in building solidarity and is built through shared activities in the treatment setting, such as cooking meals together or sharing childcare:

I guess the big thing is I have a real desire to get better, that’s my biggest thing and then also, well for myself and for my kids. I kind of feel I guess, not that I want to be in rehabs forever, but I find it’s really lovely to be around people who understand what you’re going through, there’s no judgement. (Jeannine, client, residential rehab)

Jeannine’s main motivation was to improve her life and that of her kids, but as she describes that goal was supported by a culture that values the building of ‘understanding’ and ‘non-judgemental’ peer relationships. Henry described something similar:

What has helped me stay has been the staff and the other peers you know, when I have a moment I want to leave. You know they sit you down and bring you into a group and you know, remind you why you are there and basically talk you out of going, just to continue staying on and getting treated. So, the staff and other peers, yeah. (Henry, client, dual diagnosis service)

These relationships were sometimes crucial in getting people to ‘continue staying on’. They set up a mutual obligation between clients and with staff to stay in treatment. Effective services understand the value of these relationships and they work to actively create them as a way to maximise therapeutic impact. This can be thought about as a ‘strengths-based’ approach to treatment because it seeks to promote a set of values and practices that recognise the resources and capacities of clients – for example, their capacity to build positive, mutually respectful relationships- and look to support and build on this to minimise risk. Moreover, this is a service-level activity that requires careful design and commitment through policy and programming, and not something that is left to individual clients through their chance encounters with other clients.

Because of the importance of client-client relationships, it is perhaps not surprising that client drop out was seen to have a negative impact. When other clients leave treatment, it becomes hard for those who stay: “too many people come and go for me. Some stay a little bit longer than others, but yeah, you’ve got to click with someone to make it work” (Jude, client, dual diagnosis service). When those who a person ‘clicks with’ leave this can undermine their own capacity and motivation to stay.

Importantly, these ‘shared experiences’ and peer relationships were not equally available to everyone. Clients who identified as LGBTQI, and those who were Aboriginal, more often talked about how they had trouble building these relationships:

I’m gay and I might benefit if there was something that was out there for the LGBT community specifically, because a lot of my community when they go into these treatment centres or rehabs, you find yourself being the minority even more so amongst the larger community of people in the rehab or service centres, so that makes it even harder for someone who’s gay to be able to stick to the program and get through it without feeling like you know, you’re in a minority of minorities [...] You feel like ... you just kind of are left out a bit from peers. (Henry, client, dual diagnosis service)

For these clients, without the same level of peer support, their ‘moments of wanting to leave’ will not be supported in the same way as for other clients with stronger peer support. Thus, while services need to actively create peer support networks within treatment settings as a way to maintain clients progress in treatment, they must also pay attention to the diversity of clients’ identities because these determine what counts as ‘shared experience’: the experiences of Aboriginal people, or those of LGBTQI people, as examples, are different to those of others.

In summary, participants found it easier to remain in treatment when they had built positive relationships with other clients. Thus, even when initial motivations varied – for example, to simply escape ‘the outside world’ - positive treatment outcomes could be bolstered if supportive and meaningful relationships among peers were made, especially if attention is paid to the diversity of experiences that clients brought with them to ensure they had some shared background with others.

#### A physical environment that is comfortable and clean

Some participants talked about the physical environment of a service – privacy, food quality, ‘nicer rooms’ – and how a clean and comfortable environment was important in keeping them in treatment. The quality of the physical environment mattered in creating positive therapeutic experiences, as Bobby (client, dual diagnosis service) describes “[I like] having your own room, so you can think.” Others talked about the quality of the food, facilities and outdoor space. The physical space of a treatment environment matters significantly, as has been shown in other research (Fraser, 2006) because it sends important messages to clients about their role in and relationship to the service. Poorly fit-out, disorderly or unclean environments reinforces existing deficit views that some substance users can hold of themselves as being unworthy and undeserving.

However, participants emphasised that the treatment model and the positive relationships they built at treatment services were more important in keeping them engaged than the physical setting. For example, Gareth (client, day program service) had been able to access private treatment, but felt that the staff and program at his current public setting enabled better and more sustainable outcomes:

I stopped looking at private because private, it’s more about nicer food, nicer rooms, but that’s it. I don’t care about that [...] the public [services] have a much better outcome. The

staff care. You end up running the rehab, so they get you doing duties. You know, they don't have paid staff. (Gareth, client, day program service)

As highlighted throughout this report, such is the importance of client-staff relationships, that participants might forego physical comfort for the sake of their treatment outcomes. This indicates the high motivation levels of clients we spoke to, who were able to make strategic sacrifices in order to increase their treatment outcomes.

#### A culture that supports self-determination

Self-determination was important to client-participants and they talked about it in a range of ways. Often, they expressed their need for self-determination in relation to no smoking policies and other rules that were viewed as overly regulatory. In fact, strict rules about smoking or other things were seen to be detrimental to clients' treatment progress, as Jude describes:

I've been ejected due to smoking in other services... You get a yellow card or orange card and red cards, that's how it was up there before and if you get a red card and you get in more trouble, then you are out. But geez, there's none of that now up there. It's much more relaxed. (Jude, client, dual diagnosis service)

Being expelled from a service for smoking seemed unnecessarily severe to Jude, compared to the 'more relaxed' setting that he was in at the time of his interview. Clients appreciation for self-determination was also expressed through their enthusiasm and gratitude at being included as active participants in the 'healing culture' at services. They valued being invited to join in the process of developing a welcoming culture within the service, as Suzie (client, residential rehab) said:

One of the things I learnt probably a little from the staff, but also from the residents who have completed the program, is how you welcome other people. So here I was welcomed with open arms and when we were getting new people in, we were reminded by staff that how you behave and how you welcome people is then how they ... it's like the vibe you give off. (Suzie, client, residential rehab)

In these examples, a sense of self-determination is set up by services by giving clients responsibilities – for making their own choices about smoking, for example, and for being part of a shared obligation to build a positive culture. These responsibilities are valued by clients because they grant a sense of self-management, autonomy and control: qualities that are highly valued in Western culture but are typically not attributed to people with addiction. Indeed, people with problematic substance use are generally seen to have failed and to be lacking self-control. In this way, services that work to build a sense of self-determination among clients are directly addressing the stigma that clients experience in this regard, a feature that is valued by many and works to support their staying in treatment.

#### Quality relationships with family and friends

Some client-participants described their family circumstances as a key motivator keeping them in treatment. This supports existing research that suggests that not only is family a barrier to treatment access but involving family in AOD treatment increases the likelihood that a person will remain in

treatment (Battams et al., 2010; Rowe, 2012). Family involvement and creating a family–professional collaborative partnership is shown to improve outcomes for the individual especially in the case of adolescents in AOD treatment (Hornberger & Smith, 2011) and increases the likelihood of sustaining their important support giving role ultimately improving treatment outcome (McCann & Lubman, 2018). Gareth (day program setting) described his family and friends as his main motivation to stay engaged in treatment: “they’re probably the only reason”. Wanting to please loved ones and build a happier and safer home and family environment came up several times. Gareth (client, day program setting) spoke of his partner and children as motivating him to take up treatment and stay the course:

I have a lovely partner, (details about his partner), yeah and together we have a nice little family, but it could be a lot better without me being addicted to drugs and we are under supervision from DOCS at the moment. My children are well fed, there’s always food in the cupboard, always got something to eat, it’s not like what you see on TV, when you see like bad households, but then again, what is a good household with someone who is addicted to drugs. (Gareth, client, day program setting)

Families acted as ‘cheer squads’ and this was an important factor for those clients lucky enough to have them:

Yeah, my family’s a big major motivator. Every time I see them, they just tell me that I’m doing well and they feel proud of me and stuff like that and yeah, and I feel a lot better. (Rhonda, client, residential rehab)

Yet, for many other clients, families played a much less positive role, and in many cases were implicated in clients’ problematic substance using trajectories, as described by Ruth:

I have a toxic relationship with mum. I did stay there for a couple of years and my drinking got worse during that time. My mother and I are just not in a good relationship and I couldn’t go back there. (Ruth, client, day program setting)

These quotes demonstrate how relationships can be productive and destructive in the substance using experiences of clients. The need to conceal addiction from a spouse (Appel et al., 2004), care for a sick family member (Rapp et al., 2006), the threat of losing child custody (Gueta, 2017; MacMaster, 2013; Woodall and Boeri, 2014), competing responsibilities of caring for dependent children and lack of family support (Gueta, 2017; MacMaster, 2013, Stringer & Baker, 2018) are often cited in existing research as barriers to treatment. Positive relationships with partners, children, parents, and friends impacted clients’ experiences within treatment: treatment completion promised a better life for them and the people they cared about. These relationships set up treatment completion as an obligation: completing treatment promised positive outcomes not only for clients as individuals, but for the other people in their lives. In this way, services that can support the involvement of positive family and other relationships will likely have more impact on treatment retention. Services that view treatment as a journey that is shared by families (rather than an individual endeavour) are likely better able to retain clients in treatment in the long term. Such an approach will be especially true for Aboriginal clients who come from collectivist cultures in which

well-being is viewed in terms of the family and community well-being, rather than individual well-being.

### Summary and implications

Participants identified some of the key enablers that support client retention in treatment. At the basic level, clients stayed in treatment simply because these services offered a rudimentary safety that was not available to them in 'the outside world'. But participants also described how specific features of the service culture mattered to client retention: that they were warm and accepting; that they supported and valued client self-determination; that they recognised the value of and actively encouraged the building of supportive peer relationships; and that they offered clean and comfortable surroundings. Factors external to the service environment were also important, including the quality of family and friendship networks that a person possessed, as improving these relationships acted as a motivator to complete treatment and the promise of making a better life for everyone.

Implications of these findings include:

Service cultures matter immensely. **Services that value acceptance, client self-determination, and peer solidarity** send important messages to clients that their lives and problems are important, that they are capable of having positive relationships with others, and that they are worthy of respect. These features strengthen the therapeutic relationships between staff-client and client-client. They set up a mutual obligation to stay in treatment. Additionally, when they are lost through staff turnover and client drop-out, they can negatively impact the therapeutic experience of clients.

Relatedly, working to build strong relationships between clients is a therapeutic approach that can feel exclusionary to clients who are LGBTQI, Aboriginal or identify with another minority. Supportive peer relationships are mostly built on having shared lived experience. When Aboriginal or LGBTQI clients use mainstream treatment services they can feel alienated and thereby miss out on an important therapeutic elements. This highlights **the value of services that are culturally-specific** (such as 'culture as treatment' approaches for Aboriginal people) and the value of cultural-competency training for staff at mainstream services.

Positive relationships with families and friends are a key motivator for treatment completion. Treatment is seen as a way to improve family and social life and this finding points to the way that **treatment is conceptualised by some clients as a shared journey, rather than an individual endeavour**. Services that can incorporate families and supportive friends in the treatment journey will likely be more successful in addressing the motivations of these clients and retain them over the long-term.

### Recommendation for increasing retention of clients in treatment

- Treatment delivery should actively encourage the building of supportive relationships between clients. This is seen as a major driver of treatment success and sends important

strengths-based messages to clients that they are capable of constructive relationships and contributing positively to the treatment journey of others.

- Services that actively encourage peer relationships must also attend to the diversity of clients' identities and experiences. Clients from minority identities will not build peer relationships as easily if they do not have a shared lived experience with other clients, such as that which comes from being an Aboriginal person or LGBTQI person.
- Increase the attention given to staff training and retention. This is because the quality and approach of staff, including that they are warm, accepting and have high expectations, is one of the main factors in keeping clients engaged.
- Services should always consider the quality of the physical environment. Sometimes a safe environment is all that clients are seeking, but also because high quality physical surroundings send messages to clients that they are valued and respected.
- Services consider the importance of the rules and regulations that they seek to enforce. Overly regulated treatment environments are viewed negatively, send a message to clients that they are untrustworthy, and mean that clients will not return if they have a choice. Additionally, the 'word of mouth' informal referral system will mean that overly regulated services will develop a reputation as such and will be avoided.

## What helps to maintain outcomes after leaving treatment?

Post treatment care was seen to be best supported by ongoing connection to formal care, such as through outreach from a person's treating service or through linking up with a self-help group (AA/NA or other 12 step groups). Good outcomes after treatment were also seen to result from the quality of skills a person developed while in treatment, namely skills in self-care, goal-setting, self-motivation, and help-seeking. There was a general sense, however, that clients' post treatment needs were not well-supported because of the lack of system integration and collaboration. Indeed, in many cases, post treatment care was dismally insufficient. Although services need to provide an exit plan, the form of aftercare provided could be as little as passing on information about treatment available elsewhere, or as Jude described being dropped off at a motel:

Once you are out the door and they got your stuff, once they drop you off at the motel, that's it you are on your own. [...] No support, nothing. They said they'll do this and that, but once you are in a motel, that's it. You have to go and find your own place or get on a train and go to (a major Australian city). (Jude, client, dual diagnosis service)

In general, participants had fewer opinions about which were the successful factors in post treatment than they did about successful approaches to aftercare. In our view, this could be because there are currently few post-care options upon which to base their experiences and views. As we will describe shortly, self-help groups may be seen as one of the best option only because there are few other models available.

### Proactive, person-centred ongoing contact

Treatment services that play an active role in establishing aftercare planning were seen to be the most successful, and clients valued the work of services that did this. In these approaches, aftercare planning was set up as part of the treatment experience by services, was started early in the treatment period, and took the form of continued periodic contact with workers from the treating service or workers in the community. Jeannine (client, residential rehab) described how formal 'outpatient' programs that were run out of the treating service were the most helpful approach for her:

Yeah and I see a therapist and I've done SMART and I've done other outpatient programs. I think outpatient programs actually from centres are really helpful as well, so once you leave to be able to continue like once or twice a week kind of thing to keep you on track in the early days, so yeah. (Jeannine, client, residential rehab)

Professional participants described proactive and person-centred aftercare as the best approach to supporting clients' long-term outcomes. Nola (stakeholder, frontline worker) said:

We link them in with a case worker very early on and that case worker follows through right till the very end of their journey, which is necessary just to have that one-to-one, you know, they have one-to-one sessions with them quite often. We have a very good cognitive program that we use because more often than not, they're a bit cognitively impaired. (Nola, stakeholder, frontline worker)

In this approach, relationships with casework staff are established early in the treatment program and solidified over the course of treatment in order to shore up the post-treatment experience and maximise the opportunity for clients to maintain their treatment outcomes. This one-on-one caseworker approach permitted a degree of person-centred care whereby the differing needs of individuals could be addressed, for example as Nola describes the cognitive needs of clients. This approach also permits attention to clients' individual journeys, their need for housing or parenting support and so forth. This was seen to be an approach that could 'travel' because clients who lived in other regions could be connected to outreach services in their vicinity:

[Clients] don't all come from local areas, so what we like to do is engage our outreach service, and the outreach service is a lot of community drug and alcohol workers will touch base with them, you know, before their sort of program has finished and then they will contact them again once they've been discharged from the service. (Nola, stakeholder, frontline worker)

Other professional staff also spoke of the value of a person-centred care approach to aftercare:

I think that person-centred care, not a one size fits all model. Being person-centred and working on what's important to that person. I think that's best practice. (Jewel, stakeholder, frontline worker)

The best approaches to aftercare were seen to be the set-up of a positive client-staff relationship that could endure once a person exits the treatment setting. Such relationships were proactively created by services, early in a client's treatment regime. These one-on-one relationships (for example, through the caseworker model) were seen to best support the individualised care needs of clients post-treatment: care that could give attention to a person's diverse needs in relation to housing, family obligations, and cognitive and other health needs, for example. At the core of this model was a view that positive social connection was a key strategy in maintaining outcomes. This view was also central to the other main model of aftercare that participants talked about, which was ongoing post-treatment support through self-help groups.

#### Ongoing peer support: self-help groups and other strategies

One of the key ways in which aftercare appears to happen is through peer support via self-help groups such as AA/NA and other 12-step groups, and SMART Recovery. Sometimes clients were connected to these groups through the proactive arrangements of their treating services, and at other times they set-up this contact themselves. Clients and professional participants saw self-help groups as a key post-treatment strategy because they offered an ongoing process of self-reflection and peer support, and more formalised support relationships such as mentors and sponsors:

Something that I haven't attempted much of, I've tried, but I'm quite ... I'm determined to is the 12-Step programs. They seem to have such a huge success rate and I've tried everything else and I've met some really lovely women there who are very supportive and I guess you get the same sort of community support that you get in a treatment centre, because they've all been through it as well and there's no judgment and the first time I went into the rooms, I was so nervous and I was like, "ugh, everyone's going to look at me" and now you realise, "actually they are happy that you're there and they've all been exactly where you are", so



that's something that will really help me when I get home (Jeannine, client, residential rehab)

Anita (stakeholder, frontline worker) also described linking clients into peer networks as key to maintaining client outcomes post-treatment:

There's peer support, there's a focus on socialisation and the factors in someone's life and encompassing the whole person, but that's a community. So, they help each other. So, I love that community aspect of recovery. (Anita, stakeholder, frontline worker)

Social isolation and abandonment were perceived to be common aspects of problematic AOD use. Therefore, community connections were seen to play a large role in maintaining client outcomes. Some professional participants suggested that such peer support could be gained in a range of ways and not just through self-help groups. Rather, it is the shared lived experience that matters to post-treatment success:

I also think peer work, people with lived experience, yeah, that's a skill in itself and I think that's really under-valued. So, I think a lived expertise, the value of a lived expertise works more than the ... what they can provide to AOD treatment in New South Wales is amazing. I think we need to focus a lot on that as well. (Jewel, stakeholder, frontline worker)

Thus, peer support is seen as crucial to both treatment completion and positive post-treatment outcomes. The manner in which the peer support is provided was seen as less relevant. Because self-help groups are widely available, even in regional settings, these are widely used as a form of aftercare. However, for those clients who do not want a self-help format, other strategies could be explored that will work to maintain peer links and the moral support garnered through shared experience during post treatment. Recent developments in phone app technologies, for example, might be preferred by some as a method of peer support during post-treatment.

#### Setting up the 'right' set of skills during treatment

Another key strategy in maximising post-treatment outcomes was concerned with building clients' skills in self-care, goal-setting, self-motivation, and help-seeking. Clients described this process as starting early in the treatment period, and professionals saw it as crucial to both the treatment and aftercare experience. Professionals, in particular, noted that the best post treatment outcomes were borne out of the skill-building work done while the client was still in treatment: "I think it's about ensuring there has been work done while they are in treatment to plan for exiting treatment." Sonja (stakeholder, senior manager).

The essential skills in this regard were seen to be about communication, self-care, goal-setting and help-seeking. For example, Suzie (client, residential rehab) described learning about communication through 'role plays on how to say 'no''. She also described improvements in her self-care skills whereby 'mindfulness is drilled into us. Nearly every day, we have at least one group or meditation. Self-care skills were also built through exercise, yoga and other activities, and clients described feeling inspired and motivated by the varied and practicable education they received during rehab:

They do a lot of groups that help, they do groups on triggers and what you have to look out for and yeah, they teach you to have routine and we also do craft and we do yoga and exercise and all that, so it's a good well rounded program, so when we get out we can continue like doing yoga or going to the gym or things like that, so yeah. I think it's fairly easy for me to get in and out (inaudible) to go home, in case I didn't want to go, but once I got home sort of ... I think it's fairly easy to get help if you want it. You got to want it for it to work. (Rhonda, client, residential rehab)

Clients described how learning these skills came with an expectation that they would use them to stick to their goals after exiting treatment. Jeannine (client, residential rehab) describes this accountability and how much she valued it:

Once you've left, they keep in contact with you for at least 3 months or maybe it's even longer, but the first few months particularly, we come up with a plan while we are in the rehab and then when we leave, they will ring and see how you're going and make sure you are doing everything we had planned to, so I think that's going to be ... I've never had that before, so I think that will be really good to have someone who knows your story but you've got to keep accountable to, so yeah. (Jeannine, client, residential rehab)

Residential rehab clients, like Jeannine, described their aftercare plans in greater detail than did other client-participants, pointing to the way that residential rehab is a model that is better set-up to establish aftercare processes for clients. Skill-building of the type described by clients was highly valued – these skills were seen to be able to substantially help them once they left the treatment setting. Indeed, some clients felt inspired by the skill-building work they did and believed it opened up a much brighter future for them.

However, relying too much on individual skill-building approaches runs the danger of overly individualising post-treatment outcomes. As Rhonda's quote above points out, when 'you've got to want it for it to work' this runs the risk of construing outcomes as a failure of personal motivation rather than as a difference in opportunity and resources. For example, professional participants tended to attribute outcomes to the client's motivation levels, as highlighted by Karl (stakeholder, frontline worker):

That's something I've noticed. If the client still wants the ongoing support, they will definitely stay in contact with us. But there are some clients, I think, if they kind of relapse or lapse, they see it as a failure and they don't want to inform us. So that's another factor I think sometimes that they drop off and don't stay in contact. (Karl, stakeholder, frontline worker)

Karl interprets post treatment experiences in terms of either 'wanting' it or not: it is construed as a personal choice. He also points out that this individualisation of the 'relapse' experience is damaging to clients because they too see it as personal failure and respond by 'dropping off' and avoiding post treatment contact. In this way, one of the risks of an overly individualised approach such as 'skill-building' is that it blames clients for their 'relapse', further entrenches the deficit views that they already hold about themselves (as failing) and results in actions to cut off what might be their only source of formal help and support in the post treatment period.

Additional problems with the over reliance on personal skill-building as a strategy for aftercare become evident when considering how such skills can be differently taken up and used by those with different resources and opportunities. Individual skill-building in relation to self-care, self-motivation and help-seeking are much less helpful to those who are exiting treatment without long-term stable accommodation, or the material resources needed to engage in self-care activities like yoga or the gym, and without the family or peer 'cheer squad' described earlier. In this way, when post treatment outcomes are construed as an issue of 'personal motivation', those with fewer resources are doubly disadvantaged because they are much less likely to be able to apply their skills and less likely to achieve positive outcomes.

#### Breaking down silos: Collaboration and organisation across service systems

The lack of collaboration across service systems was seen by professional participants to be one of the key problems in providing adequate post treatment care and the government was seen to have a role in addressing this. For example, Anita (stakeholder, frontline worker) said:

I think that, you know, if there was ... from a state level or even a federal level, if there was, you know, a focus on organisations partnering with each other as planning a funding model and working with ... some people are siloed from mental health to AOD to hospitals to homelessness. I mean, it's completely segmented. It's segmented for us, let alone the clients [...] I see a lot of cross-sector navigation and beautiful work done by individuals who are sort of leaders and senior people within their organisations, but it doesn't go beyond that and we're all under the same bureaucratic traps. So, policy obviously, but yeah, fundamental realignment of our values and ethos as a society as well is, you know, without community push for that. (Anita, stakeholder, frontline worker)

This is something that is also identified in existing literature whereby a higher degree of integration between primary health care, mental health services, and AOD treatment services would allow for extended engagement with services and better care coordination (Ashford et al., 2018; Berends & Lubman, 2013; Savic et al., 2017; Substance Abuse and Mental Health Services Administration, 2016). This existing research identifies that a lack of stable housing during and after treatment leaves clients vulnerable to 'relapse', exacerbation of mental health problems, and a return to homelessness, a pattern that is found in the literature internationally (Wittman, Polcin & Sheridan, 2017) and in the Australian setting (Lubman, Manning & Cheetham, 2017). Other professional participants in our study noted these gaps and described how the service system was hard for clients to navigate and this set them up as being 'too difficult':

Unfortunately, in their words, the system is hard to navigate, and the reason they've kind of had to wait until they've been either made to or hit rock bottom and been referred somewhere. It wasn't clear to them how you access support and that felt like they're always putting them into the too hard basket. (Jewel, stakeholder, frontline worker)

Here, Jewel suggests that the system itself is responsible for positioning clients as deficient: the siloed nature of the service system makes it very difficult to navigate, yet it is clients who are seen to be 'too hard' because of their inability to navigate the system. She suggests that staff in a range of

sectors can hold this view – not just the AOD sector – and that this can shut down clients’ opportunities for cross-sector support. This suggests that workforce development across sectors might be needed in order to shift views that AOD clients are “too hard”.

Clearly a more user-friendly system is required in order to support post treatment outcomes. As Anita describes above, the only people who can successfully navigate such ‘bureaucratic traps’ and ‘cross-sector navigation’ are ‘leaders and senior people’ with exceptional skill. The need for coordination between the various health and social services is also identified in the existing Australian research. Savic et al (2017) suggest that high quality integrated care should include three main factors: staff training to identify and respond to client need beyond one’s own area of expertise; expectations for coordination across services be built into the specifications of commissioning agencies and supported through funding; and that case management should be considered as a way to respond to clients with complex needs. Our findings support this: both professional and client participants spoke positively of the person-centred casework approach and its capacity to support clients in system navigation. Yet our findings suggest that more work is needed to strengthen interagency relationships and in improving workers understanding of the services available in their locales; and there remains a substantial need for policy makers and program designers to build better alignment of service systems so that it is not left to individuals (some of whom are in crisis) to navigate these silos themselves.

### Summary and implications

Participants identified several strategies that they believed supported post treatment success. Connection to self-help groups was commonly reported and this was arranged by the treating service or set up by clients themselves. Formalised ongoing contact with staff at the treating service was also reported. In both approaches, setting up these arrangements early in treatment was seen to be important, as a way to ensure continuity of care. And, in both approaches, the guiding idea was to maintain social connection with others – either peers or workers – as a lack of social connections was seen as a key driver of ‘relapse’ in the post treatment period. The other key factors seen to support post treatment success were having the ‘correct’ skill set to maximise self-care and help-seeking, and having sufficient integration and collaboration across the service system in order to ease clients’ pathways to the support that they need, such as housing, mental health care and so forth.

Below we consider some of the implications of these findings.

***Support from others with lived experience is a key enabler of success in the treatment journey***, this time through self-help groups as way for clients to maintain their positive post treatment trajectories. However, the self-help format is not attractive to all clients and, if this is to be a key factor in post treatment success, then it’s important to consider other models of peer support. One option is to offer one-on-one peer support through an extension of or outreach component of existing consumer participation activities at treatment services.

***Post treatment outcomes are seen to rest heavily on the individual skills that are built during the treatment period***: self-care, goal-setting, self-motivation, and help-seeking. These skills are

developed on the premise that they will be used by clients to manage their choices and decision after they leave treatment. Clients valued this skill-building and saw it as important to their treatment, and they appreciated and respected that they were accountable to their treating service to keep up with these skills after leaving. Yet, as our findings reveal, this focus on individual skill-building also means that 'relapse' is construed as a failure in personal motivation, which can be experienced by clients as yet another example of their shortcomings, sometimes leading to them 'dropping off' contact with service providers, who are often their only source of formal help and support. This problem stems from the strong biomedical tradition in AOD treatment that emphasises individual modification over changes that would see better organisation and resourcing of the service system.

Relatedly, some participants identified that ***better cross-service integration and collaboration enabled better client outcomes*** during the post treatment period. Clients found it difficult to address their needs for housing, mental health and other care because of the complexities of navigating service systems; yet this inability to navigate the system was sometimes seen as a failure on the part of clients who were thought to be 'too hard', rather than as a problem with the set-up of services. Shifting views of clients as 'too hard' is important, but it is also important to strengthen the service system by: improving interagency links and strengthening relationships between AOD staff and those in other social and health services; increasing the knowledge among non-AOD staff about the availability of treatment, the various models available and the impact that treatment can have; advocating further for changes to the top-down organisation of service provision.

As with earlier sections of this report, we found that ***post treatment success happened differently for those with fewer resources***: for those who were homeless on entry to treatment, they were faced with similar problems when they left when the housing organised for them was often transitional or short-term. In this way, the factors that enable the best post treatment experiences must pay attention to how disadvantage is implicated in these trajectories. The emphasis given by participants to person-centred casework is clearly one way in which socio-economic disadvantage can be addressed.

Overall, it seemed that ***participants had fewer opinions about best practice for the post treatment period than they did about successful approaches to treatment entry and retention***. We wonder if this is because there are currently few post-care options upon which to base their views. Despite this lack of options, participants agree that there is a need for better aftercare and that it needs to be person-centred to address the diversity in individual needs, that it needs to support ongoing positive social connection, and that it needs to be supported by a better integrated service system. Any policies and activities directed at building more options for aftercare should ensure that these are evidence-based, and currently there is a lack of multidisciplinary research evidence about post treatment trajectories.

#### Recommendations for maximising positive outcomes after treatment exit

- Consider the range of models though which to offer peer support in the post treatment period, including but not limited to self-help groups.

- Individual skills-development is seen as a major strategy for aftercare. However the focus on individual skill-building means that 'relapse' can be construed as a failure in personal motivation, which can be experienced by clients as yet another example of their shortcomings, sometimes leading to them 'dropping off' contact with service providers, who were often their only source of formal help and support. Consider ways to better communicate to clients that 'relapse' is not a personal failure.
- Find ways to extend person-centred casework so that it can be provided for all people upon treatment exit. This is a strengths-based approach that supports client self-determination and helps to address the particular disadvantages of each individual. Acknowledge the risk of this approach, which is that it depends on the quality of one-on-one relationships and that if these fall over (due to staff retention problems, for example) this can be challenging for clients.
- Given there are currently few models for aftercare, advocate for more research on the post treatment period so that new policy and practice in this area is evidence-based.

## CONCLUSION

In this research we sought to document some of the main enablers to successful treatment at each of three stages: the pathways into treatment, the treatment episode itself, and the post-treatment period. As part of this, we wished to understand how issues of access and equity impacted each of these periods differently, in order to identify factors that might increase equity across the system. Our observations suggest that inequity seems most pronounced in the early stages, when clients are seeking treatment places and navigating referral pathways. While some clients had friends or family that organised their referrals, contacted the treatment service and supported them during intake (and, indeed, some family members paid the treatment costs), other clients got into treatment only through the intervention of an engaged police officer or because it was a court requirement. One method to ameliorate this inequity could be to draw on the existing expertise of people with lived experience, who are viewed by most clients as a valuable source of knowledge, skill and support. It is also clear that the pre-treatment experience is important in shaping subsequent experiences: each experience in the treatment system helped clients to navigate subsequent entry attempts, suggesting that any positive engagement in the referral system, even if it does not result in treatment entry is worthwhile. If this engagement is warm and welcoming, it can smooth that way for entry next time, and for this reason all entry attempts should be carefully managed by staff with the most suitable skill set.

The need for warmth and acceptance is carried forward into the experience of the treatment episode itself, and service 'cultures' that were warm and welcoming were important in maximising retention. Service cultures that valued the building of supportive client-client relationships were valued because they recognised the agency of clients and their capacity for healthy and productive relationships. Yet, this approach involved inequity for clients who were LGBTQI or Aboriginal who felt it was sometimes difficult to build solidarity with other clients who did not have the same histories. For some minority-identified clients, this made them feel alienated and they missed out on important therapeutic elements of treatment.

The impact of inequity in the post treatment period is less clear and this is because participants appeared to have fewer opinions about best practice in this period than they did about successful approaches to treatment entry and retention. We wonder if this is because there are currently few post-care options upon which to base their views. Our observations suggest that the provision of post treatment care depended on the type and quality of the treatment service that the client was leaving, and that while some clients were connected to aftercare during their stay in treatment (this happens, for example, in residential rehab), others received much less intervention and could exit treatment with very little support in place.

Some important themes run throughout the data that warrant mentioning. Peers play an important role at all stages of the treatment journey and consideration should be given to develop creative ways in which this kind of peer support can be improved. Additionally, the importance of client self-determination is evident at all stages. Clients benefit from the opportunity to choose the treatment model and service that best suits them, and from experiencing a service model that recognises and engages their capacities. This demonstrates that strengths-based approaches are crucial to

maximising positive treatment journeys because they work to undermine views that people with addiction problems are deficient and incapable of change. These are views that clients can hold about themselves but that the best service models can undo in the process of high-quality treatment.



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# Barriers and enablers associated with access and equity in alcohol and other drug treatment: A review of the literature

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## **Key findings**

*Early engagement matters* – the ‘critical periods’ for drop-out and ‘relapse occur in the early stages of treatment and then again in the early post-treatment period. Efforts focussed on these two periods will best support long-term engagement with care.

### **What supports uptake and maintenance in treatment for individuals?**

*Addressing widely held beliefs that treatment is not needed* or not beneficial, or too difficult and that success rates are low. By highlighting the success stories and positive outcomes of treatment people may be more motivated to take up and maintain treatment. In addition, better supporting people’s desire to attempt withdrawal and substance use management on their own or with different forms of support, ie, those beyond existing formalised AOD services.

*Support for co-occurring mental health problems:* for example, through clinical staff that are trained to treat both AOD and mental health problems; and by increasing understanding about how mental health conditions play out as perceived ‘poor behaviour’. Issues of stigma, long waiting lists and lack of adequate training and professional development in effective comorbidity treatment influence people’s ability to access appropriate treatment.

*Support for other life complexities:* such as poor housing conditions, restricted income and debt and criminal records.

*Support for families:* concern for family members is a significant barrier, especially around implications of AOD treatment on child custody arrangements. Involving family in AOD treatment increases the likelihood that a person will access and remain in treatment.

*Improving knowledge about and quality of treatment for methamphetamine use:* The reasons for low treatment seeking among methamphetamine users has been attributed to the perceived poor orientation of services to this particular group, lack of information about their treatment options, and low confidence in the effectiveness of available treatments.

*Clarifying expectations, communication and ‘rules and regulations’ at AOD treatment services:* service users appreciate the high expectations that services have of them, but want clear and fairly applied application of rules and regulations.

*Reducing the stigma attached to substance use:* uptake and engagement would be improved through reducing discriminatory behaviour (of wider society and health care professionals), and reducing the shame and embarrassment experienced by people wanting treatment.

*Legacy of criminality associated with illicit drug use:* Criminal histories have multiple impacts on AOD treatment uptake and engagement by 1) curtailing their capacity to enter treatment if they have parole condition to meet; 2) impacting their capacity to secure and maintain employment, housing and so forth, during the post-treatment period; 3) AOD treatment itself signifies engagement in illegal and/or socially deviant behaviour.

### **What supports uptake and maintenance in treatment at the systemic level?**

*Systemic support* to provide adequate administrative support and fiscal resources within services themselves to reduce among other things admission difficulties; appropriate workforce development support to minimise burnout; and overall adequate availability of treatment services and places at those services.

Increasing the availability and quality of pre-treatment programming to engage clients while they wait for availability of intake.

*Increase the availability of services and the level of integration* with other services such as primary health and mental health care.

### **What are key ways services can intervene?**

*Decreasing the entry barriers to treatment.* Current barriers represent a significant deterrent to treatment from the perspectives of both staff and service users. This is especially true for women, those with co-occurring mental health issues and those with criminal histories, and these groups are arguably those who are most in need of treatment services.

*Working to reduce stigma:* There is a pressing need to reduce stigma through expanded education to reduce discriminatory beliefs held by professionals and others in the AOD sector. Stigmatisation can be countered by policy development, training and support to increase staff awareness and skills, and inclusion of a peer support workforce.

*Recruit and retain qualified staff:* High staff turnover is identified as a major challenge but planning for such contingencies and developing formalised program procedures is thought to minimise disruptions.

*Expanded education and staff training, including trauma informed care* is identified as a possible way to better respond to clients' needs and maintain engagement at all levels of treatment.

*Consider options to better include and support family members* in the treatment trajectory, in particular in relation to adolescents, parents with children, and spouses.

### **Introduction**

Participation in alcohol and other drug (AOD) treatment has been associated with positive outcomes among treatment seekers but it is also typical for treatment seekers to 'relapse' or, in other words, to leave treatment before completion or to return to treatment multiple times. This means that people seeking AOD treatment often have trajectories of care that involve multiple periods of engagement, drop-out and re-engagement (Ashford, Brown, & Curtis, 2018; Brecht & Herbeck, 2014; Smyth et al., 2010; Manning et al, 2017). In an attempt to better understand the factors involved in these complex trajectories, we undertook a review of existing literature. The review used two guiding questions:

1) What are the main barriers to accessing AOD treatment, and what works to maximise access to AOD treatment and maintain engagement in ongoing care?

2) What is the specific role of AOD services in maintaining engagement and what specific practices work best?

This review was focussed on treatment barriers and enablers, as reported from studies that took place in Australia and internationally. Literature was sourced from published peer-reviewed sources and publicly available grey literature focusing on the years from 2010 to the current time (however several important studies were included in this review that were prior to this period). The papers included discussion regarding treatment outcomes, and identify individual and systemic barriers to treatment, while also highlighting practices and strategies that work well to keep people engaged in AOD treatment and continuing care.

#### Patterns of engagement, drop-out, re-engagement

There are several points along the AOD care trajectory that are identified as critical for engagement. The first point is treatment uptake, and Treloar and Holt (2006) identify that, of the people who use illicit drugs and wish to stop using, only a small proportion end up engaging with treatment services. Thus, while treatment programmes may be effective in reducing and/or ceasing use, a range of barriers prevent these programs being widely adopted in the first place. Secondly, among individuals who do receive treatment, nearly two-thirds experience a recurrence of substance use within months of entering treatment (Brecht & Herbeck, 2014). The rate of early 'relapse' is thought to be of particular concern because treatment clients who experience early relapse are likely to continue to have more difficulty maintaining their treatment goals in the short-term (Charney, Zikos, & Gill, 2010). For example, research suggests that earlier periods of abstinence are predictive of longer-term abstinence (Hser, et al., 2007, 2015; Laudet, A. B., & Stanick, 2010; Orliková, 2018). Thirdly, post-treatment appears to represent the period of greatest risk, whereby the highest rates of 'relapse' tend to occur early in the post-treatment period, with greater abstinence rates associated with staying in treatment for at least six months (Brecht & Herbeck, 2014; Hughes et al., 2004; Stone et al., 2018). Thus, there is a "critical period" very shortly after treatment discharge when clients are particularly susceptible to relapsing from their treatment goals, highlighting the importance of continued aftercare (Bailey, Herman, & Stein 2013; Smyth et al., 2010). The remainder of this review examines the factors that support uptake of and maintenance in AOD treatment and identifies some of the key ways in which services can intervene to support treatment maintenance.

#### **Barriers to AOD treatment**

People seeking AOD treatment often experience complex needs in other areas of their lives. Research indicates that AOD treatment clients are significantly more likely to access and remain in treatment if these other needs are addressed by service providers (Appel et al., 2004; Fiorentine, Nakashima, & Anglin, 1999; Treloar & Holt, 2006). Research suggests that individuals with co-occurring mental health and substance use disorders access treatment at substantially lower rates compared to individuals without such co-morbidities (Abuse, 2016; Harris & Edlund, 2005). The interplay of addiction and mental health problems together with other life complexities such as poor housing conditions, restricted income and debt and criminal records adversely affect their ability to engage and remain in treatment (Teesson et al., 2005; Treloar & Holt, 2006; World Drug Report, 2018). Pennay and Lee (2009) found that service providers identified a shortage of clinicians trained to treat co-occurring AOD and mental health issues as a barrier to accessing treatment. Service providers identified the perceived 'poor behaviour' of people with mental health issues as a barrier to accessing treatment in some cases, with some people who are seeking treatment and others who

are already enrolled in treatment being asked to leave and return once their behaviour was more stable (Pennay & Lee, 2009). The lack of clinical comorbidity workforce development, practice supervision and skills training mean that people requiring care for co-occurring mental health and substance use disorders often receive inappropriate care focussing on either mental health or AOD problems rather than integrated comorbidity care (De Crespigny et al., 2015).

Homelessness especially among young people with comorbid disorders is cited as one of the most significant barriers to AOD treatment. Health professionals noted that it was really difficult to treat and assist young people to deal with a substance use whilst they remain transient or homeless. Homelessness frequently contributed to further complexities and barriers such as involvement in the juvenile and criminal justice systems (Szirom, King & Desmond, 2004, Appel et al., 2004). The stability and quality of accommodation affected people's ability to access treatment, with people living in unstable, unsafe or poor quality accommodation reporting adverse effects on their general wellbeing, their ability to attend or participate in treatment, and their mental health status (Treloar & Holt, 2008)

The criminality associated with illicit drug use often acts as a barrier to treatment and produced difficulties when treatment users were looking for work, trying to secure accommodation or dealing with support agencies related to the drug or mental health sectors (Begun, Early, & Hodge, 2016). Meeting parole conditions or completing a previous course of treatment acts as a social signifier of criminality and drug use, and treatment clients with criminal records generally felt that the possibility of rehabilitation was not available to them because of these social stigmas (Treloar & Holt, 2006)

Stigma is a complex construct that can come from many sources and may manifest as a barrier in several ways. Stigma and discriminatory behaviour against people who use drugs is common and can deter people from seeking help due to feelings of embarrassment or shame (Hammarlund et al, 2018). Injecting drug use is a highly stigmatized behaviour and people who inject drugs receive harsh condemnation (Capitania & Herek, 1999; Frable, 1993) often portrayed by the media as being dangerous, irresponsible, and weak (Conrad, Garrett, Cooksley, Dunne, & MacDonald, 2006; Herek, Capitania, & Widaman, 2003; Tindal, Cook, & Foster, 2010). These negative views are not limited to the general public but often held by health care workers too and expressed in the form of negative staff attitudes and behaviours towards service users (Lubman et al., 2014; Treloar & Hopwood et al., 2006; von Hippel, Brener, & Von Hippel, 2008; Wilson, Brener, Mao, & Treloar, 2014). Self-stigma occurs when people internalize these stereotypes and blame themselves for their illness (Corrigan, Watson, & Barr, 2006; von Hippel, Brener, Horwitz, 2018) and it is this self-stigma and embarrassment that is often reported as a barrier to seeking treatment (Kenny et al., 2011; Meade et al., 2015; Pennay and Lee, 2009). Stigma is experienced differently by people depending on their specific experiences and conditions. For example it is one of the biggest barriers to effective treatment for pregnant women with many who turn up at services reporting feeling unwelcome and judged (Eggertson, 2018).

One of the main barriers to accessing treatment identified by people who inject drugs concerns family (spouses, parents, but most importantly dependent children). Appel et al. (2004) found wanting to conceal addiction from a spouse was a significant barrier to AOD treatment. Others report having to care for a sick family member as a main reason for not being able to seek treatment (Rapp et al., 2006). However, of great concern to many treatment seekers is the implications of AOD treatment on child custody arrangements with the threat of losing child custody being a significant barrier to treatment (Gueta, 2017; MacMaster, 2013; Woodall and Boeri, 2014). The competing



responsibilities of caring for dependent children was another barrier for mothers that was often interrelated with lack of family and social support (Gueta, 2017; MacMaster, 2013, Stringer & Baker, 2018). Relationship-level barriers become even more complex when both members of a couple are seeking treatment, since treatment facilities can have a “No Couples” policies (Simmons & McMahon, 2012) that prohibits couples from entering the same program together. Services felt this policy improved treatment outcomes by allowing individuals to participate more fully and more effectively in their own recovery. Such an individualised approach to treatment has been criticised for ignoring the highly social nature of drug use and the way it is related to other complex life issues, as outlined previously.

The issue of treatment services being specifically relevant or effective for methamphetamine is another barrier to treatment. Research found amphetamine users are more reluctant to attend services that also treated heroin users; heroin use being heavily stigmatised from the perspective of amphetamine users (Kenny et al., 2011; MacMaster et al., 2008; Pennay and Lee, 2009). The reasons for low treatment seeking among methamphetamine users is not clear, but the poor orientation of services to this group, lack of information about treatment options and little confidence in the effectiveness of these programs has been reported as barriers to access (Cumming et al., 2016; Kenny et al., 2014; MacMaster, 2013). In addition, the perception of negative staff attitudes towards methamphetamine-using clients was also indicated as a barrier by methamphetamine users (Kenny et al., 2011; Woodall and Boeri, 2014).

Lack of clarity and communication of rules and regulations within treatment services, particularly residential services are other common complaints. For example, young service user’s report that they appreciate the high expectations that services have for their behaviour and treatment progress, but they need to know that the rules and regulations are fairly applied to them and others (Bryant, 2018). They also seek recognition for their achievements prior to entering AOD treatment, wherein they have ‘survived’ sometimes traumatic and difficult situations and feel like they should be provided the opportunity to contribute to the ‘rule-making’ at AOD services, a process that can be well-supported through consumer participation in policies and programs at AOD services (Bryant et al, 2008; Brener et al, 2009). Other issues reported is the lack of information being provided to clients prior to entry into a treatment service and/or situation where information provided prior to entry is directly contradicted upon entry (Lubman et al., 2014). In addition, clients perceptions and fear of inadequately controlled physical pain in treatment and, for some experiencing emotional distress that was relieved while using drugs, are relevant concerns impacting their decisions as to whether they will access and/or remain in treatment (Stumbo et al., 2017).

Other individual barriers commonly cited in literature include a belief that treatment was not needed or not beneficial, negative social support, fear of treatment and of uncontrolled pain, privacy concerns, time conflict and self-reliance and/or a desire to withdraw on their own (Cumming et al, 2016; Kenny et al., 2011; MacMaster, 2013; Meade et al., 2015; Stumbo et al., 2017; van der Pol et al., 2013). The desire to attempt withdrawal on their own is often cited as an important perceived treatment barrier for both methamphetamine and cannabis users, and therefore individuals who are non-treatment seeking should be offered self-reliant interventions, such as internet based that have been shown to be low-cost, easily accessible and effective in reducing use (Tait et al., 2013; Carroll et al., 2014).

Systemic barriers in the treatment field are prevalent from the perspective of professionals, staff and stakeholders engaged in various AOD treatment services (Ashford, Brown & Curtis, 2018; Hunt et al., 2017; Priester et al., 2016). Systematic barriers to AOD treatment commonly reported in the

literature include administrative burden, lack of fiscal resources and workforce development support, lack of adoption of evidence-based practice strategies, limited treatment services, recovery support programs and available places and admission difficulty, lack of collaboration and leadership and technological resources.

Treatment services with substantial entry barriers are a significant deterrent to treatment access from the perspectives of both staff and service users, especially for women in custodial settings with co-occurring mental health and substance use disorders who face complex psychosocial challenges at community re-entry (Grella et al, 2004; Johnson et al., 2015). Access to treatment on release from prison is critical for people with problematic alcohol and drug use (NADA, 2013). There are many triggers for women relapsing to substance use when re-entering the community, including problematic relationships, exploitation, lack of social support, and limited resources for addressing these and other challenges (Johnson et al., 2015). Lack of resources to provide treatment and / or discharge planning, long wait times for appointments, lack of trust of institutions or inability to follow through with the treatment plan are cited as barriers to treatment (Priester et al., 2016). Service provision is a structural barrier to treatment access for such individuals. Service barriers such as organizational red tape involved in treatment enrolment such as the need for identification, medical plans, prioritisation processes (Appel et al., 2004, Lubman et al, 2014), and the lack of pre-treatment programming that can engage clients while they wait for availability of intake and treatment appointments all act as a barrier to treatment (Johnson et al., 2015). These service barriers individuals encounter have the potential to impact the accessibility of treatment services (Grella et al., 2004; Johnson et al., 2014, Lubman et al., 2014). The transition from custodial settings to AOD treatment setting can be challenging for both the client and the staff and require time, acknowledgement, emotional safety and motivation from both sides in order to understand the impact of time in prison on the person's behaviour and enable the shift required for the client to experience positive treatment outcomes (NADA, 2013). More treatment and support services, particularly pre and post residential treatment programs, in areas where current access is limited can help increase access to AOD treatment.

What is the specific role of AOD services in maintaining client engagement?

Primary treatment for AOD in Australia is offered through specialist services that include opiate substitution programs, rehabilitation services, detoxification services, mutual aid or self-help groups and a range of therapeutic counselling services. This section addresses issues raised in the literature focused on improving service provision in order to maintain client engagement.

When looking at what works best in AOD treatment, a number of factors are evident: clearly defined and effective management structures and procedures; appropriately trained staff and ongoing staff development programs; good multi-strategy and collaborative approaches; strong leadership; adequate and continuing funding; clearly defined realistic objectives aimed at the provision of appropriate services that address community need; honouring community values, cultivating key leader support, and utilising peer staff (Brown et al., 2016; Cummings et al., 2016; MacLean et al., 2012; ).

In order to ensure continued engagement with treatment, services need to focus on certain key areas:

There is a pressing need to reduce stigma through expanded education to reduce discriminatory beliefs held by the public, professionals, and among the recovery community (Ashford et al., 2018). Stigmatisation can be countered by policy development, training and support to increase staff awareness and skills, and building relationships with specialist services. Additional education and the

use of evidence-based practice is also needed including more complete experiential training regarding shame and trauma. Trauma-informed care not only realizes the widespread impact of trauma and understands potential paths for recovery but also helps recognize the signs and symptoms of trauma in clients, families and staff (SAMSHA, 2018). Staff training in identifying and responding to needs beyond clinicians' primary area of expertise is considered important to maintaining engagement at all levels of treatment (Savic et al., 2017).

There is a need for additional treatment services or a higher degree of integration between primary health care, mental health disorder services, and substance use disorder services (Ashford et al., 2018; Savic et al., 2017). Traditional separation of substance use disorder treatment and mental health services from mainstream health care has created obstacles to successful care coordination (Substance Abuse and Mental Health Services Administration, 2016). Integrated and coordinated models that operate across primary health and specialist AOD services are important and would allow for extended engagement with services (Berends & Lubman, 2013; Treloar & Holt, 2006, 2008). In reality, even when patients are engaged with AOD services they will need access to primary healthcare for other medical concerns and ongoing care. Integrated models would allow for clients to maintain their connection to AOD and primary health care during and after treatment. There is a need for coordination between various AOD services to ensure greater continuity of care within a client's treatment journey and a coordination between AOD and non-AOD services such as housing, mental health and community health to ensure multiple needs are met (Savic et al. 2017).

Substance use and mental illness is not uncommon among individuals who are homeless (Gillis et al., 2010) and the lack of stable housing after treatment leaves them vulnerable to a relapse in substance use, exacerbation of mental health problems, and a return to homelessness, a pattern that is found internationally (Wittman, Polcin & Sheridan, 2017) and in the Australian setting (Lubman, Manning & Cheetham, 2017). Efforts to address homelessness among people with alcohol and drug problems is essential to ensure uptake and maintenance of treatment (Lubman, Manning & Cheetham, 2017; Sun, 2012; Wittman, Polcin & Sheridan, 2017). Co-ordinated models can reduce practical barriers by simplifying referral pathways between services and improving organisational efficiencies and patient outcomes (Schulte, Meier & Stirling, 2011).

Staff familiarity with patients receiving AOD care reduces feelings of stigmatisation, fear and avoidance. However, the ability of individuals to enter, remain and be successful in drug treatment can be affected by factors well beyond those under their immediate control. Complex vulnerabilities beyond drug dependence and poor mental health commonly affect service users' capacity to participate and remain in treatment. Addressing these complex and ancillary needs is vital to improve treatment effectiveness and the lives of those coping with co-occurring drug and mental health problems (Treloar & Holt, 2008). There is also the difficulty in recruiting qualified staff and high staff turnover rates in the AOD treatments services, especially in the Aboriginal AOD field which further exacerbates these problems (Gray et al. 2009; 2010; 2014). While high staff turnover is a major challenge, planning for such contingencies and developing formalised program procedures to minimise disruption and loss of 'corporate knowledge' if staff leave can help to mitigate this problem (Gray et al., 2014).

There is a need for greater collaboration between health services that involve a reduction in the philosophical differences between various elements of the care continuum, medication-assisted recovery and abstinence-based recovery (Ashford et al., 2018; Bosch & Mansell, 2015). The different and often conflicting philosophies underpinning drug treatments can be seen as both a barrier and an enabler to treatment at personal and systemic levels (Treloar & Holt, 2008). For

example, some programs which are abstinence-focused often do not allow clients to remain in the program if they relapse compared to other programs, particularly those operating within a harm reduction framework, that make greater allowances for clients.

The treatment philosophy is seen as an important factor in recruiting, training and maintaining a drug treatment staff as well as affecting trust, communication and referral between services.

Services could benefit from increased communication frequency and style, increase the collaboration with outside organizations, and to raise the bar in relation to ethical standards (Asford et al. 2018). Difficulties in accessing a service because of geographic proximity, lack of transportation or resources to obtain transportation and operational hours are often cited in the literature as a barrier to treatment access (Adler, Pritchett, Kauth, & Mott, 2014; Levesque, Harris, & Russell, 2013; Muir, Powell & McDermott, 2012). By offering flexible service provision, such as increasing evening and weekend hours or providing satellite or home-based services for individuals in rural areas, may address these challenges. Integrated service systems with integrated communication between services may further enhance treatment access (Kola & Krusynski, 2010). Additional resources are needed to support treatment services as well as to improve and increase technological infrastructure (Ashford et al., 2018). For example, a communication tool such as a website or mobile app that is available with information on housing, employment, education, and pro social resources that can be easy to navigate and assist both client and service provider. Research has shown that modest additional resources can lead to increased capacity to deliver services; improved case identification; increased client engagement; improved interagency and community collaboration; and development of more appropriate assessment tools and resources (Gray et al., 2014).

Research suggests that involving family in AOD treatment increases the likelihood that a person will access and remain in treatment (Battams et al., 2010; Rowe, 2012). Family involvement and creating a family–professional collaborative partnership is shown to improve outcomes for the individual especially in the case of adolescents in AOD treatment (Hornberger & Smith, 2011). Family involvement helps to develop collaborative partnerships that bring the expertise, resources, and experiences of families and professionals together and is necessary to help individual, particularly adolescents, access and remain in treatment. In addition, affected family members who access formal and informal help sources for themselves are more likely to sustain their important support giving role (McCann & Lubman, 2018). As concerns around family (as discussed earlier) is a significant barrier to entry, involving the family from the beginning is an important way to improve treatment outcome.

This review provides a basic framework for identifying key individual and systemic barriers to the success of AOD treatment, and provides some recommendations to resolve these identified barriers in order to maintain continued engagement in treatment services.

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