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Mental Health Commission

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# Consumer perspectives: Alcohol and other drug and mental health services



# Acknowledgements

Workforce Development at the Mental Health Commission would like to sincerely thank all of the consumers who took part in the focus groups for their time, their honesty and their generosity in sharing their experiences, thoughts and opinions with us. The insights gleaned across the four focus groups have been invaluable in providing us with a window into the experiences of those with co-occurring alcohol and other drug and mental health issues when accessing services.

The Government of Western Australia acknowledges the Traditional Owners throughout Western Australia and their continuing connection to the land, waters and community. We pay our respects to all members of the Aboriginal communities and their cultures; and to Elders past and present.



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# Executive Summary

This report details the experiences shared by 24 individuals, who self-identify as consumers of alcohol and other drug (AOD) and/or mental health treatment services, during a series of focus groups conducted in December 2018 as part of the Keyworker Plus project (the Project). The Project was developed and implemented by Workforce Development (WFD) at the Mental Health Commission of Western Australia (MHC) with funding from the Western Australian Primary Health Alliance (WAPHA). The Project's goal was to deliver AOD-related training to mental health workers across Western Australia (WA). This was intended to provide skills, knowledge and support to mental health workers who work with clients who use AOD, to ultimately lead to better outcomes for people who use services. It was determined that the focus groups would enable the experiences of people who use services to inform and enrich the training content and provide insights into the lived-experiences of navigating service systems. It was intended that mental health workers who attended the training as a part of the Project, would be able to use these understandings to inform the development of therapeutic relationships with their clients.

For the purpose of this series of focus groups, 'treatment' encompassed all of the services and supports that were available to people who had engaged in the mental health and AOD sectors. Each focus group explored the consumers' experiences of how and why they accessed treatment, as well as their experiences once they were in treatment. The questions further investigated the consumers' perspectives on how they felt treatment could improve. The themes that were identified from the focus group discussions are summarised below.

## **Barriers to service engagement:**

- **Stigma**

Many of the participants felt that the way broader societal attitudes, values and beliefs influence mental health, AOD use, treatment trajectories and self-concept contribute to and maintain stigma. It was felt that people in general hold stigmatising attitudes towards people who use AOD in particular, and to a lesser extent, people who experience mental health issues. Participants reported that this awareness impacted on the consumers' feelings of self-worth.

It was felt by participants that there is a general tendency within society to hide negative and unpleasant feelings. This tendency was felt to impact on the consumers because they did not feel comfortable talking truthfully about their issues, and this contributed to feelings of being stigmatised. Furthermore, it was felt that when people don't talk about their AOD and mental health issues, others are unable to learn from their experience, or develop a context for what they might be experiencing themselves. For example, any of the participants stated that this meant they did not have a concept of what 'problematic' AOD use looked like, nor did they know what type of help was available.

In addition, it was noted that people who use AOD and/or have mental health issues can internalise these broadly held community attitudes and this will impact on their self-worth and their beliefs about their worthiness of receiving treatment. This was a factor in treatment seeking, and engagement once in treatment.

- **Fear of consequences**

Many of the participants stated they did not access services for a long time because they were fearful of the consequences of doing so. These concerns included: fear of the involvement of child protection services; fear of raising traumatic histories; fear of receiving a diagnosis; and concerns that seeking treatment for AOD or mental health issues use might lead to a punitive backlash. There were also concerns that seeking treatment in a mental health setting would force them to address their AOD use, even if they did not wish to do so.

- **Personal conceptualisation of issues**

How the participants framed their own issues was a determinant of their pathways into treatment. Some participants disclosed that a barrier to accessing mental health services was that they did not identify their problems as being symptomatic of a mental health issue. Others stated their conceptualisation of what a mental health issue was tended to be 'extreme' and so, if they did not identify as being 'extreme' they did not consider they had a problem with their mental health.

Participants also spoke of how a general lack of community conversation around what problematic AOD use looks like made it difficult for them to develop a frame of reference for their struggles with their own use. Simply put, they did not know what 'problematic use' looked like.

- **Structural barriers**

A number of structural barriers to accessing treatment were identified across the focus groups. Participants raised that it was often difficult to find out what services were available, what treatment options were available within services, and how accessible and affordable they were. This difficulty in knowing how and where to find this information was cited as a reason for not accessing help.

For some participants, there was a sense that the public sector was underfunded and understaffed, and this impacted the quality of care available to people with complex needs. They further reasoned that the cost of the private sector meant that this avenue to treatment was out of the reach of many.

The presence of waitlists was also seen as a barrier to treatment engagement by participants across all the focus groups because it was felt that being placed on a waitlist once treatment had been sought impacted on change motivation. Furthermore, given that motivation to change tends to ebb and flow, there was concern that treatment might become available when motivation was low and be refused.

There were often other obligations that served as barriers to accessing help, such as Centrelink obligations, court requirements or childcare issues.

- **Factors influencing sector pathways**

One objective of the focus groups was to explore the factors that determined which sector (i.e. mental health or AOD) people initially accessed and why. From the discussions, it appeared that most participants did not make an informed choice about which sector they initially accessed. Rather, the issue that was causing the greater problems tended to determine where treatment began. For example, for some, their treatment pathway began in the AOD sector as factors associated with their AOD use, such as involvement with the criminal justice system, brought them to the attention of services, and this influenced their referral pathway.

Some participants had only engaged in one sector. Some stated that all of their needs had been met by the one sector, thus, they did not feel the need to access the other. Others preferred the treatment options in one sector over the other. For example, one participant did not wish to access the mental health sector because they did not wish to be prescribed medication.

### **Participants' experiences of the roles services have played in their recovery:**

- **Peer support**

The majority of the consumers felt that access to peer support was significantly beneficial for their recovery. It was largely agreed that access to support from someone with a lived-experience of AOD and/or mental health issues was important for feeling validated and understood. Furthermore, it was felt that the peer workforce were able to share their knowledge on effective treatment with consumers.

However, some participants disclosed costs to working as a peer in a professional environment. There was difficulty maintaining the 'peer' aspect of their identity when working in a professional environment. This often took the form of concerns about how much of the 'peer' identity was appropriate to disclose to professional colleagues.

There were also some issues raised about the management of the peer workforce. While participants felt that services were obligated to provide the same level of support and supervision that is afforded their professional staff, this did not always occur.

- **Autonomy and choice**

Participants across all the focus groups felt that being afforded the autonomy to make their own choices was essential for recovery to be possible. This took the form of having the sense that they could decide for themselves what the focus of treatment was, to decide which concern (AOD use or mental health) got addressed, having autonomy and choice around their medication, and the autonomy to define issues and needs in one's own terms. It was agreed that outcomes tended to be better when these choices were present.

Conversely, participants felt disempowered when they were not afforded the autonomy and choice to contribute to the discussion around their treatment. This was viewed as unhelpful because individual circumstances and preferences were not taken into account. For example, not being referred to services of their choosing undermined a sense that their needs were being taken into account by workers and services.

- **Service aspects**

There were several service aspects that were considered important to recovery. Participants noted that effective communication was beneficial. Services that communicated their role in the client's recovery were considered helpful, as were those who listened to their clients and were able to facilitate specific needs, such as the gender of their counsellor.

Conversely, a service aspect that was considered detrimental to recovery were policies that were experienced as punitive. One participant disclosed that they were required to fill the next-of-kin section of forms with fake names because they did not have a next-of-kin. Others discussed being denied pain medication because of their AOD use history. Another participant described having their treatment cancelled for missing an appointment.

A number of participants felt that services needed to manage tension between the requirements of their funding agreements and meaningful engagement with clients.

- **Relationships with workers**

The participants cited that the most helpful aspect of treatment was feeling that their workers cared for them and cared what happened to them. This was true for them whether they were engaged in the AOD or mental health sector. They reported that when being valued in this way was communicated to them, their outcomes improved. Aspects of the client/worker relationship that communicated caring included: the sense service that they were being listened to; worker belief in the client; being afforded the time to develop a trusting relationship with their worker; and feeling accepted without judgement.

There were also practical aspects to workers communicating that they valued their clients including: regular home visits from workers; workers across different services communicating with each other; and workers being transparent with their clients about the information they have shared with other workers.

Conversely, a negative experience with a worker can derail treatment seeking. For example, feeling uncared for had the opposite effect on their treatment outcomes. When they felt judged as a 'hopeless case', and a 'recidivist drug user', they doubted their capacity to change.

This section highlights that how workers communicate and what they communicate about their client's capacity to change, can impact on clients' feeling of hope and optimism about their own recovery.

- **Staff turnover**

Staff turnover was cited as an issue across the participants in all of the focus groups. It was reported as being frustrating and had a negative impact on change motivation. Participants stated that they grew frustrated at having to repeat themselves and relay their story every time they had to engage with a new worker.



- **Siloed services**

There was consensus from participants that the mental health and AOD sectors being separate from each other enabled a silo mentality to develop between the two sectors and this led to service users receiving support from services that were not necessarily well equipped to manage people with co-occurring issues. Furthermore, many of the participants voiced that they had experienced exclusion from one sector because of their co-occurring issues. This sometimes led to feeling forced to address issues they weren't ready to. For example, being told they must address their AOD issue before engaging in mental health services or vice versa.

Some participants felt that siloed services meant that they were potentially being treated by staff who do not have the skills to manage co-occurring issues. Furthermore, it was felt that the siloing of the sectors tended to diminish the relationship between the two issues within individuals.

It was noted by participants that services in the broader health and welfare sectors also tend to operate independently of one another. This, too, was deemed unhelpful.

### **How services and service delivery could be improved:**

- **Broader conversations**

Participants across the focus groups discussed the need for more honest conversations at a community level. It was thought that if negative human experience were more widely discussed, greater understanding of the collective human experience would develop and help alleviate stigma and some of the other fears people had when it came to admitting to an AOD and/or a mental health problem.

It was further thought that normalising the discussion of difficult emotions could have a preventative effect by teaching children how to identify when they're not managing well, emotionally and mentally. This could lead to a generational change in the impact of stigma and other barriers around treatment seeking.

The involvement of peers was thought to be able to drive broader community conversations. It was felt that, if people with mental health and/or AOD-related issues shared their experiences, the wider community would become more aware of the range of people who can become impacted by these issues. This would help to break down stereotypes and help others identify that they have problems that can be treated.

Normalising conversations that support destigmatising people with mental health and/or AOD-related issues can, not only change the way people see them, but also change the way they treat them. One of the focus groups extended this notion to how people treat each other generally. It was raised that, perhaps, if people were nicer to each other, less people may develop significant mental health issues.

- **Expanding the peer workforce**

Expanding the peer workforce was considered a way to improve outcomes for service users. Peers can help put new clients at ease when entering treatment for the first time.

They would be able to help alleviate anxiety by greeting new clients in the reception area and helping them orient to the service.

A stronger peer workforce could also provide advocacy and mentorship for people who are too unwell, or for other reasons unable to ask for help. It was noted that there are services that people need to engage with, whether they want to or not and these services could provide an opportunity for peer workers to engage with vulnerable people who would not otherwise access services. This could lead to people seeing the benefits of therapeutic engagement.

Expanded peer involvement could also provide benefits to people exiting treatment. Peers could provide proactive engagement once clients cease treatment. This would allow for people to maintain connections and provide an open avenue for support to those who do not seek aftercare.

- **Service aspects**

A range of ideas for service improvement were considered. Enhancing the variety of treatment options was suggested as a way to capture the broad range of issues that people with mental health and/or AOD-related problems are often faced with. Among the suggestions were: a central hub where people could drop in for support, advice and advocacy; short-term rehabilitation to fill the gap between weekly counselling and long-term rehabilitation; and better follow-through and aftercare. There were also suggestions that more services with less criteria for entry would make treatment accessible to a broader range of people. It was further argued that the public and private sector could work in better concert with each other to improve access to services for people.

The consumers in this series of focus groups maintained that all services in health and welfare settings should maintain the principles of trauma-informed care and practice.

- **Worker aspects**

The discussion about the aspects of the client/worker relationship that could improve treatment outcomes concerned the balance of power in the relationship between client and worker. It was felt that the process for service users to voice when they did not 'fit' with a worker was difficult to initiate because of a perceived power imbalance. There were concerns that there would be consequences if this issue was raised.

This series of focus groups has highlighted that when workers honour the client's change agenda, change is made. Conversely, when workers attempt to drive the agenda, clients can feel uncared for and be more likely to disengage. When workers facilitated a partnership between client and worker, rather than an expert/recipient dynamic, this enabled the client to feel in control of their own treatment and improved outcomes.

It was acknowledged that, sometimes workers' caseloads and other job requirements made it difficult for them to fully engage with their clients and did not necessarily mean they were 'not caring'.

- **Integrating the AOD and mental health services**

There was common agreement that mental health workers and AOD workers should be in the same service and would ideally be skilled in working with people with co-occurring issues. This would mean that it was possible to have their needs met by one worker, rather than rely on a number of services. Alternatively, AOD and mental health services could co-locate, making access to these services easier. Staff in both sectors would also benefit from more integrated training, and that this would ultimately benefit consumers with co-occurring AOD and mental health issues.

An expansion of the Alcohol and Drug Support Line (ADSL) to include information, support and referral into mental health sector was raised by participants who noted that having this type of service for people with mental health issues could fill gaps in service delivery for clients and, potentially, lessen the strain on services.

# Notes on language

The language used to describe a person who uses alcohol and other drugs (AOD) and/or has a mental health issue can vary considerably across time, sectors, context and jurisdictions. The focus groups and subsequent report uses the term ‘consumer’ as defined by Clarke and Brindle (2010, p. 13):

“A consumer is someone who uses, has used, or is eligible to use alcohol and other drug services. It includes those people who are refused service or refuse service. It also includes family, friends and significant others of people who use services, regardless of whether or not they directly use services themselves. People affected by AOD policy and laws are also considered consumers.”

Clarke and Brindle’s (2010) definitions refer specifically to people who use or are eligible to use AOD services. In the context of this report, these definitions will also refer to people with similar associations within the mental health sector. Therefore, the word ‘consumer’ encompasses the broad range of people who may be impacted by AOD use and/or mental health issues. The phrase ‘service user’ is used to describe a person who has engaged in AOD and/or mental health services generally, and ‘client’, which describes a person who has engaged in a specific service. This report uses the three terms throughout as appropriate.

The personal pronouns ‘they’, ‘them’, ‘theirs’ and ‘themselves’ have been used throughout this report instead of ‘he/him/his’ or ‘she/her/hers’. This decision was made because the facilitators did not wish to make assumptions about the gender identity of any of the participants. Furthermore, it was felt that this approach would ensure the confidentiality of all of the consumers who participated.

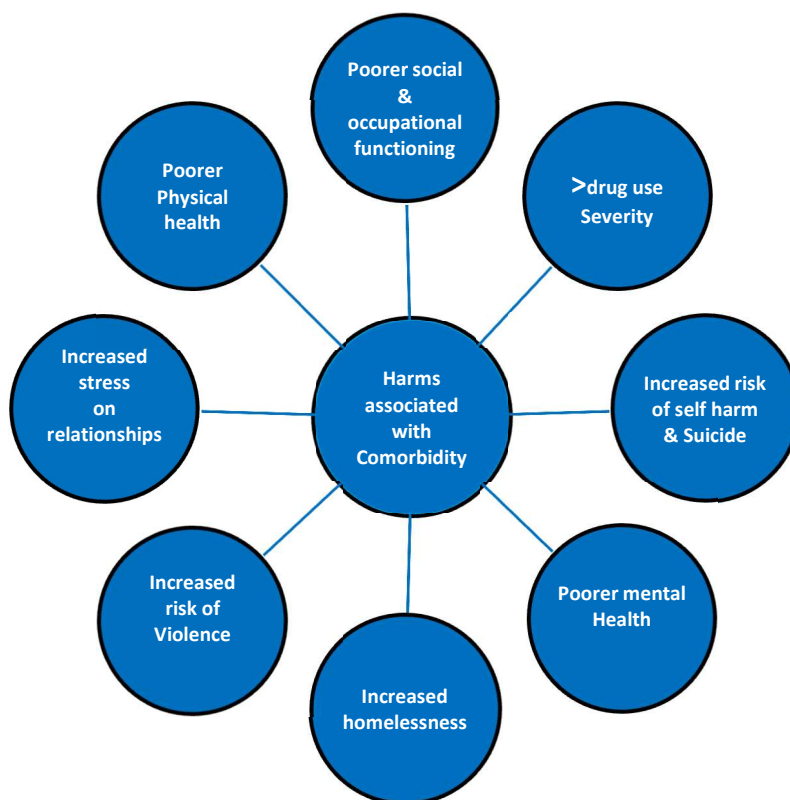
Person-first language is used throughout this report. This means that the person is placed ahead of the issue. For example, participants are described as a ‘person who uses AOD’ rather than as an ‘AOD user’ or a ‘person with a mental health condition’ rather than a ‘mental health patient’. Placing the person first acknowledges that a person is defined by more than their AOD use or their mental health issues, and that these are only a part of who they are. Furthermore, the use of stigmatising language such as ‘addict’, ‘alcoholic’ or ‘borderline’ or ‘schizophrenic’ is avoided. It has been noted that the language used when referring to people with mental health issues and/or who use AOD can make a difference to the way they are perceived by others and themselves (MHC, 2019).

This document uses the term ‘co-occurring’, rather than ‘comorbid’ or ‘dual diagnosis’ to describe the co-occurrence of AOD and mental health issues within individuals. It is recommended that the word ‘morbid’ is not used as it carries negative connotations (MHC, 2019). The phrase ‘dual diagnosis’ tends to be problematic because it assumes that people only have two diagnoses. Indeed, people may have a number of complexities, or may be having difficulties without an associated diagnosis. Drug and Alcohol Findings Hot Topics (2016) recommend that “... rather than thinking of people with dual diagnosis as having two support needs, it may be more useful ‘to acknowledge that they have complex needs’, both directly related to and extending beyond their substance use and mental health” (para. 3).

Terminology which forms part of a direct quote will be used verbatim. It is acknowledged that all of the consumers in this series of focus groups, and more broadly, retain the right to refer to themselves in any manner that they see fit.

# Introduction

Co-occurring AOD and mental health issues are common. In Australia, it has been estimated that up to half of all people with mental health issues will experience co-occurring AOD-related issues (Teeson et al., 2014). Furthermore, people with co-occurring AOD and mental health issues tend to have worse outcomes than those with either one or the other (Marel et al., 2016). As Figure 1 shows, the associated harms tend to be worse across a wide range of social, physical and psychological issues. Only a small percentage will seek treatment, and for those who do, treatment is often inadequate (Teeson et al., 2014). Given that people commonly experience co-occurring AOD and mental health issues, it is imperative that workers in both sectors have an understanding of the problems facing people with co-occurring issues. This includes how the issues interrelate and how this might impact on treatment engagement.



**Figure 1:** Harms associated with co-occurring AOD and mental health issues (Marel et al., 2016, p.14.)

Workforce Development (WFD) at the Mental Health Commission (MHC) supports the AOD sector, mental health and other human service providers to enhance their capacity to engage and respond effectively to people experiencing AOD-related issues. One of the strategies used to achieve these aims is to deliver tailored training programs to the AOD and allied sectors which WFD has provided for more than 20 years. As part of its commitment to training workers with clients who use AOD, it has offered 'Keyworker: AOD Skills for Mental Health Clinicians' (Keyworker) training to government mental health clinicians in the Perth metropolitan area since 2006. According to National Health Service United Kingdom (n.d.) a

'keyworker' is described as: "...a care professional who takes a key role in coordinating the care of the patient and promoting continuity, ensuring the patient knows who to access for information and advice" (para. 2). The Keyworker training offered by the MHC aims to equip Government mental health workers with the knowledge and skills to work with clients who use AOD. The aim is not only to increase their confidence when working with clients who use AOD, but also to enable them to support these clients in accessing and engaging in the AOD sector. Furthermore, the training enables them to share their knowledge with their colleagues. The training is held over three days and includes:

- Drug categories and their effects
- Harm minimisation
- Impact of the complex issues underpinning AOD use and mental health issues
- An overview of trauma informed care and practice
- Key models used with clients who use alcohol and other drugs
- Raising the issue, using a screening tool and conducting a brief intervention
- Conducting a brief motivational interview
- Identifying appropriate referral options for clients who use AOD and when referral is appropriate

In 2018, the Western Australian Primary Health Alliance funded WFD at the MHC to conduct the 'Keyworker Plus' project. The project was delivered from October 2018 – June 2019. The funding enabled WFD to offer the Keyworker training in regional WA. In regional WA the target audience for the Keyworker training was expanded to include non-government mental health clinicians to maximise the reach of this training.

The project further complemented the training by providing an opportunity for mental health workers to do a four-hour per week placement at an AOD service for six months across the Perth metropolitan area and in two regional pilot sites (Great Southern and Pilbara). It was envisioned that having AOD and mental health workers working alongside each other would facilitate the development of greater understanding and shared language across the two sectors. It was intended that this would improve communication and thus, client outcomes.

In developing the Keyworker Plus training package for mental health workers, WFD identified the importance of embedding the consumer voice in training and other WFD activities around co-occurring AOD and mental health conditions. Consumer participation across the mental health and AOD sectors has grown in recent years. It is broadly defined as "the process of involving health consumers in decision making about health service planning, policy development, priority setting and quality in the delivery of health services." (Clarke & Brindle, 2010, p.13). According to the Network of Alcohol and Drug Agencies (2019), benefits of consumer participation include "...improvements to principles related to human rights; health outcomes; relationships; service delivery; as well as accreditation and legal issues" (p.6).

In WA, the MHC supports and encourages AOD and mental health consumer participation using a variety of approaches ranging from informing and consulting consumers to co-designing services and citizen-led initiatives. These approaches are underpinned by the

Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018 – 2025 (Engagement Framework). The co-designed Engagement Framework and Toolkit aim to assist government, non-government organisations (including private enterprise), and the community to effectively engage and work together to achieve better outcomes for people whose lives are affected by mental health issues and/or alcohol and other drug use. Consumers, families and carers can also use the Engagement Framework and Toolkit as a guide to what they can expect from services in relation to their participation in the service.

WFD felt that consumers, as the ultimate recipients of workers' knowledge and skills, have the right to inform both sectors on best practice. Furthermore, if workers are to truly work in partnership with their clients, they should also be recipients of consumers' knowledge and skills. From this understanding, it was decided that a series of focus groups in which consumers had the opportunity to explore and express their experiences was an opportune way to develop an understanding of consumers' lived-experiences. This was with a view to not only enhance the Keyworker training content, but also to add to existing and future WFD training. This would ensure that the lived-experiences of consumers in WA has the opportunity to be heard and understood by WA workers.

This series of focus groups was also intended to build on the insights gleaned from a similar focus group that was held by WFD in 2016. In the 2016 focus group, eight Self-Management and Recovery Training (SMART) peer support workers were asked a range of questions related to their experiences of recovery. Where applicable, this report will refer to findings in this earlier focus group. A copy of this report, Consumer perspectives: Alcohol and other drug recovery (MHC, 2016) can be sourced via this link:

<https://www.mhc.wa.gov.au/media/3380/consumer-perspectives-aod-recovery.pdf>

The current focus groups were designed to complement the Keyworker Plus project by providing an opportunity for people with a lived-experience of AOD and mental health issues to share their experiences of accessing services across both sectors. It was envisaged that providing an opportunity for consumers to explore barriers and facilitators to treatment, discuss what works well and areas for improvement across both sectors, then incorporating these consumers' voices into training content would lead to better understanding of the issues for workers, and better outcomes for clients.

WFD identified four broad objectives to be explored by the focus groups:

- To gain a better understanding of the service experiences of individuals experiencing AOD and mental health issues who may or may not have engaged in services in both sectors
- To understand the barriers to service engagement for those who haven't engaged in services in either sector
- To gain an insight into participants' experiences of the roles services have played in their recovery
- To learn about what services are currently doing well and what could be improved.

These objectives were explored across five questions (see Appendix B).



The recommended number of participants in focus groups for non-commercial purposes is five to eight (Krueger & Casey, 2009). Thus, it was decided to recruit a maximum of eight participants in each focus group, which allowed for cancellations. Participants were recruited by emailing a detailed flyer to consumer groups across the mental health and AOD sectors. Peer-led organisations were also contacted in an effort to reach consumers who hadn't engaged in treatment in either sector.

In December 2018, four focus groups were held, each lasting approximately 90 minutes. There were four participants in Focus Group 1, nine in Focus Group 2, six in Focus Group 3 and five in Focus Group 4. All participants were remunerated for their time, in accordance with MHC's Consumer, Family, Carer and Community Paid Partnership policy. Light snacks were provided during each focus group. All focus groups were facilitated by two Senior Workforce Development Officers, as well as an Assistant Project Officer who provided administrative support.

No demographic information was collected from the participants, nor were details regarding their AOD or mental health issues or service use. It was felt that this was unnecessary because the exercise was concerned with a broad view of experiences. The only criterion for eligibility was a lived-experience in AOD and mental health issues.

All participants signed consent-to-participate forms (see Appendix A) prior to commencing their focus group. Each focus group began with a preamble detailing the nature of the group, an acknowledgement that the topics discussed might raise issues for individuals and assurances that individual safety was a priority. All participants were advised that they could leave at any time. Given concerns that the conversation might raise some sensitive issues for any of the participants, each group was asked that, if they needed to leave the room during the session, they indicate they were not distressed by giving a 'thumbs up' signal as they left otherwise one of the facilitators would follow them to check how they were feeling. Each focus group allowed the time for a debrief session after the recorded sessions to give the participants the opportunity to discuss any issues that may have surfaced during the discussion.

The four focus groups were audio recorded, then transcribed. The transcripts were analysed for themes as a whole, rather than as four individual sessions. This report will explore the themes that have been identified under the four broad objectives of the focus groups. It will also discuss themes that emerged outside of the intended framework. All discussions refer to the participants' experiences generally, unless explicitly stated.

The themes and quotes explored in this report were initially used to enrich the theoretical content of the Keyworker Plus training program by adding the real-world experiences of consumers. The value in 'humanising' training content cannot be overstated. Workers are given an opportunity to reflect upon the impacts of service delivery in a way that may be otherwise unattainable. For this reason, it is envisaged that the themes identified will continue to enhance the content of other training events delivered by WFD. This approach will ensure that workers continue to be made aware of the service experiences of the people who access them.

Quotes from the focus groups are highlighted in italics throughout this report. It was felt important that, in writing this report, the main focus continued to be the voice of the consumer. Some quotes have been edited for clarity.

# Themes

## 1. **Barriers to service engagement**

Marel and colleagues (2016) note that research indicates that people with co-occurring issues do benefit from treatment. However, people who don't access treatment often have significantly worse outcomes than those who do. It was therefore felt that an exploration of what stops people from accessing services, would help develop an understanding of what might need to change in order to facilitate vulnerable people seeking treatment.

The first objective was explored by asking each group:

1. If you haven't engaged in either sector, why not?
2. If you have only engaged in one sector, why?

It was hoped that there would be the opportunity to explore reasons that people did not engage in services. However, all of the participants had engaged with AOD and/or mental health services. This is likely explained by the difficulty in accessing people who haven't attended services. Nevertheless, all of the focus groups did spend time discussing the barriers and issues that kept them away from services prior to accessing a service. Several key issues were identified from the ensuing discussions and will be discussed as follows.

### **Stigma**

***"Well I can answer that straight off the bat – fear, shame and judgement."***

Stigma is defined as, "... a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society" (World Health Organization, 2001, p. 16). Participants considered it a significant barrier to treatment seeking and was raised across all focus groups.

The way broader societal attitudes, values and beliefs influence mental health, AOD use, treatment trajectories and self-concept and contribute to and maintain stigma, was explored at length. It was felt that these discussions provided important context because many of the issues raised, concerning treatment across the AOD and mental health sectors, had their roots in these broader societal influences.

The participants across all focus groups indicated that they were aware that people generally held stigmatising attitudes towards people who use AOD in particular, and that this awareness impacted on their feelings of self-worth. For example, some of the participants spoke of how feeling the need to keep problems hidden contributed to feelings of shame:

***"It was - that lack of the broader community understanding of issues and what's actually happening in society around drug and alcohol use and accessibility. The normalisation of the experience for people and for families. It's just so stigmatised and ashamed and hidden so disclosure is really – it's not forthcoming from people."***

And:

*“It’s also – it’s not a very broad community conversation so it’s really kind of shame-inducing for families to acknowledge either their kids or their loved ones have issues. So it’s hidden.”*

It was also felt that the more common media portrayals of methamphetamine use in particular, potentially added to stigmatising moral arguments against AOD use, such as that people who use AOD are bad or weak or immoral. Some participants suggested that the generation of fear created another barrier between people who do use AOD and the wider community:

*“At the moment there is a lot of fear, you know. Like ‘Oh! Ice is bad!’ – but there is a lot of fear that creates that kind of barrier instantly, so the media doesn’t help at all.”*

For many of the participants, stigma tended to be felt in relation to AOD use, rather than mental health issues, as illustrated by the following quotes:

*“...because it’s so much easier to say I was diagnosed with a mental health problem than it is to say I’m an addict.”*

And:

*“I do think the stigma around mental health in general is getting better, but AOD not so much.”*

One of the participants described feeling that they had been stigmatised by workers as a result of their drug use, and this resulted in no follow-through with their mental health:

*“I think the other factor in that – because my drug use was obviously chronic, I don’t think anyone bothered ... because I was a lost drug addict, I wasn’t worth the time or the effort to engage with a service or to follow up with a plan or any lines of referral because I just – I wasn’t going to achieve anything because I was obviously a chronic addict. No one ever presented any mental health options, ever. Often when I’d disclose ... in that period you’d get 24 hours, 24 to 48 hours I think, to see the psych on site and – it would always – I remember just being discharged. It was like, chronic drug problems, that’s it. Catch ya, bye.”*

Other participants reported that stigma around mental health issues played a role in whether they sought treatment. This included stigma experienced within families. For example, one participant described how feeling ‘put down’ by their family for expressing a desire for treatment for mental health issues added to their mental distress:

*“...so it’s a lot of emotional trauma as well. So, if you took those steps to go to counsellors and so forth, that was just not on and you would really get put down for that. I would quite openly say ‘I’m not feeling too good about this, that and the other. I think I might go speak to a doctor’ and the putdown was unbelievable. So that affected [me] for a long time.”*

The idea that there is a general cultural tendency to hide negative and unpleasant feelings was explored. For example, one of the participants articulated:

*"...but people don't talk about their internal conflict and the ways in which they go about their life and the struggles they find with relation to fitting into society. That kind of conversation isn't on the table. It's always hidden and hopefully they'll sort themselves out, obviously when they don't that's when you do maybe get the help, if you don't die beforehand."*

A number of participants indicated that the broader tendency to keep negative feelings hidden impacted them personally because they did not feel comfortable generally with expressing how they truly felt. Consequently, having a sense of this can lead to the wearing of proverbial masks that project 'everything is fine'. For example:

*"That was part of my problem, was making everything look ok and on the inside I'm dying."*

This can lead to them not being taken seriously when they do ask for help:

*"...when you got to breaking point, your – getting completely broken ... For me, I was ticking the boxes, but inside I was completely broken so when I reached out for help I got 'you're alright! What're you talking about? You're fine!'"*

Some of the participants reflected that this lack of general conversation meant that they were unable to learn from others, which provided no context for what they might have been experiencing. For example:

*"There was – I don't know how it is now, but there was no kind of conversation around alcohol and other drug use, the harms in relation to that and where to go if you needed help with it. Or if you thought a friend needed help or anything like that. That sort of wasn't a conversation either. So I just sort of found myself in it and continued on until it was problematic."*

The conversations led to discussion about perceptions about the tendency within the community not speak openly about struggles, which can contribute to stigmatising people who do use drugs. For example, one participant raised the point that whilst it is normal for people to have negative experiences in life, these experiences are generally not normalised in our society – there is a tendency to minimise struggle. This can contribute to the stigmatising of people who use AOD because the wider community may not see AOD use as a coping response to negative experiences:

*"And it's just around this community conversation ... and what we do in response to that in a variety of means. It's not normalised, so – particularly drug and alcohol [use] so – 'that lot over there – that's what they do.' [For] Other humans – it's not ok to say 'I do that too.'"*

One participant described how the stigma and secrecy around AOD use meant that they did not have a concept of what 'problematic' use looked like, nor did they know what type of help was available:

*“It’s not talked about in the community. I think that’s part of why I had no clue of what was available – I just had nothing. No clue that my use was problematic and that, actually, there was help.”*

The discussions further highlighted the negative impact of general societal views towards mental health and AOD use. A number of participants described the impact this had on their own self-concept and whether they sought treatment:

*“...because I knew what the general feeling towards anybody with either mental health or AOD was and it wasn’t great. So it hardly propels you to want to seek help and while you think you’re functioning well enough to hide it, and you are functioning well enough to hide it, and knowing what would happen if people discovered you, you definitely try to keep that all quiet.”*

For another participant, they felt that aspects of drug use contributed to the experience of stigma:

*“I guess, even for syringe users you’re really judged even when you go to like – with our business, going to the chemist to purchase syringes, like the people there. Just everywhere you go, so you’re like more and more on this downward spiral...”*

One of the focus groups discussed how broad, societally held, stigmatising attitudes can lead to ‘otherising’ people who use illicit drugs. They further explored the hypocrisy of this. For example, one participant emphasised the absurdity of some drugs being acceptable, but others not:

*“Everyone thinks it’s great to be on psych drugs. Like ‘go to a psychiatrist, you crazy son of a bitch. They’ll put you on medication, you’ll take it for the rest of your life, but you’ll be grateful for it’ and the person sitting next to you says ‘yeah well I’m just going to take heroin for the rest of my life because that’s how I’m going to manage my condition.’ And they say ‘no! You can’t be addicted to drugs! That’s just being a prisoner!’”*

Another participant humorously illustrated this point:

*“Imagine a normal person saying ‘I go to the pub every Friday, I don’t know, I just can’t seem to stop myself. There must be something wrong with me.’”*

It was noted that people who use AOD can internalise these broadly held community attitudes. This is an important consideration because they may begin to believe the messages they receive about people who use AOD. This can impact on their perceptions of worthiness of treatment and support. The following quotes encapsulate how problematic this can be:

*“So, a big part of why I didn’t access treatment is because I knew my drug use was my responsibility. I was the one responsible for all of that, therefore I kind of forfeited my right to any help because I was the one causing the problem. I didn’t deserve actually [getting] health or mental health or any other service because I was inflicting it on myself. I couldn’t fix it either. I couldn’t fix myself and all the awareness I had*

*around my inner drivers just made me more helpless because I had no capacity to stop what I was doing. I still – I knew – and even though I had a sincere desire to stop, I didn't have the understanding that actually my brain was chemically hijacked as well as my body being – all of the physiological stuff as well as the spiritual and emotional side of addiction. I just thought I was fundamentally flawed because as a human being because in the face of some pretty extreme consequences I still made the decision to keep going.”*

And:

*“... and I would also say, you know, from my own experience that I didn't feel that I was capable enough or big enough to deal and change everything at once in my life and also how I live my life up to that point – was I worth even getting that help, did I deserve that support and help to change all that in my life? I think it was a lot of self-doubt and self-criticism that stopped me from addressing everything at once.”*

And:

*“... We're not that far away from prohibition, you know, where attitudes were about – and I'm talking AOD now, not so much mental health – that anybody who uses drugs every day is a loser. That's just a general community attitude, but because of that, and growing up with that ideology and knowing that's a part of our society, we're not measuring up ourselves when we turn around and pick up drugs and start using drugs. So the first thing I did was hide it. I wasn't out there about it. Sure, I'd drink in public, that didn't worry me, but my drug use was very much hidden behind closed doors. And it was only when I disclosed it that I actually went into treatment and recovery. So, the stigma, I think, partly comes from myself. My ideas of what I should and shouldn't be doing and what's acceptable and not acceptable in society. I had never looked at it as I do now, where the reason I picked up drugs was because there was a mental health problem there in the first place. I was in my 50s before I could recognise that.”*

This internalisation can lead to self-stigma:

*“Because we're judging ourselves so hard – well, for me, I'm judging myself so harshly. I think everybody else is going to be on that bandwagon.”*

And:

*“For me, it was really about self-stigma and discriminating against myself...”*

Interestingly, it was noted that many of the problems in life faced by people with co-occurring AOD and mental health issues were the same as those faced by people who don't have these concerns. It was referred to by one of the participants as the 'common human experience' and serves as a reminder that people will manage life's challenges in myriad ways:

*“It is that kind of disclosure around – it's just human conflict and struggle and the various ways by which we address that or attempt to address that in our lives,*

*whether they're helpful or not ... but people don't talk about their internal conflict and the ways in which they go about their life and the struggles they find with relation to fitting into society. That kind of conversation isn't on the table."*

And:

*"And that ... normalising experience in both ends of the spectrum, like down here and up here – this is a human thing. This is not just for people down here; this is across the – it's a collective human experience."*

These quotes provide some insight into how these consumers see the community's perceptions of AOD use, the people who use AOD, and their families, manifest in the lives of these people. They further add to the large body of literature documenting the damaging effects stigma has on people who use AODs and/or have mental health issues and further highlights its role as a barrier to seeking treatment (for e.g. see Australian Injecting and Illicit Drug User's League, 2015; National Academies of Sciences, Engineering and Medicine, 2016; Lancaster, Seear & Ritter, 2018). It is concerning to consider that many of the participants indicated they might have sought treatment much sooner, when their problems weren't as overwhelming, if they had felt less judgement about their AOD and mental health problems. By stigmatising people with AOD and/or mental health issues, the wider community continue to 'otherise' an entire section of the 'collective human experience'.

### ***Fear of consequences***

***"Exposing myself in that way, because being involved in drugs and stuff. You know, like, I just felt I was in the wrong and exposing myself in that way I could get myself in trouble."***

The fear of the consequences of attending a service was identified as having a significant impact on motivation to seek treatment. These fears were wide-ranging. For example, one of the participants cited fear of the involvement of child protection services if they attended treatment. Exacerbating the fear of having their children taken away was the fear that this would also mean losing housing and income:

*"...and you're more than likely going to have your children taken off you, to lose your income - I don't want to say I was having children for the income - or your housing, so it's not a helpful experience. You know full well you're not going to access it because the consequences are just really going to exacerbate your issues."*

Fear of raising traumatic histories was also cited as a barrier to accessing treatment. Often, even though there was acknowledgement that addressing issues would ultimately be beneficial, the fear that raising distressing memories may lead to feeling unsafe and could be overwhelming. For example, one of the participants disclosed:

*"...what I'd like to draw your attention to is that it's great to do these programs, but if it brings back such horrific trauma, you go home unsupported."*

The fear of receiving a diagnosis and what that may entail was raised as a barrier to initially seeking treatment by a number of participants. For example, one participant stated:



*“...fear in admittance, because once you admit to something and go seek help, you become a label.”*

This may also be related to the fear of being outed as a person who uses drugs, and the stigma associated with that.

For others, there was concern that seeking treatment for AOD or mental health issues use might lead to a punitive backlash:

*“... like with the fear of using, like if you go in to get help you might be like, blacklisted or like alerts [put] on your name or something and then, you know, saying like ‘I use drugs, am I going to end up in the lock-up?’”*

And:

*“For me, mental health was a no-no. I don’t know if it was a movie I saw or what, but in my brain, it was if you go mental health, you’ll never come out ... there’s something really wrong with you and once you get there, there’s no coming back, it’s final. That’s it.”*

One participant stated they were less concerned with seeking treatment for their mental health issues than their AOD use. This was because they were worried that AOD treatment would focus on getting them to stop using, even if they weren’t ready. There appeared to be a sense that they might not be in control of the treatment focus in AOD:

*“Seeking help for mental health issues really came a lot easier to me, but with the AOD stuff it was more like, is my use really that bad, really? Like, ‘I’ve got friends that drink this much’. And then it was drug use on top of that and it was like ‘am I actually going to stop using, why would I go and seek a service if I’m not actually planning on stopping using? I’ll just hold off until I’m ready to stop’. But even then, it was still – I was scared that they might try to make me stop too soon or send me off to rehab when I wasn’t ready for it.”*

When these fears and expectations are considered, both sectors may benefit from exploring ways of communicating with the wider community of what treatment entails, to allay some of the concerns that people who would benefit from treatment might have.

### **Personal conceptualisation of issues**

***“I was thinking I just lacked life skills and that, and I didn’t really understand that a definition was certain mental health issues ...”***

A range of factors were identified as influencing how the participants framed their issues and how this impacted their pathways into treatment. For example, participants across all focus groups disclosed that a major barrier to attending a mental health service was not being able to identify that their problems were symptomatic of a mental health issue. One participant articulated this:

*“I knew I was different in one sense but I didn’t have any understanding that I had a mental health issue.”*

Another highlighted that having a mental health issue can *feel* normal:

*“That’s the pervasive thing about mental health though, isn’t it? You think it’s reality and everything is normal, but sometimes it isn’t.”*

Even recognition that ‘something really bad’ was going on was not sufficient for one of the participants to define it in terms of mental health:

*“I had my first suicide attempt at eight, so looking back now I know that there was something really bad going on there. I didn’t see it as mental health either. I know that sounds crazy, looking back now, but anyway.”*

Others described how their conceptualisation of what a mental health issue was tended to be at the extreme end:

*“And with depression and anxiety – I never saw those as mental health issues. I always saw them as something that was transient and would pass or whatever. But for me, ‘mental health issues’ was people who were unable to function. You know, like needed a carer. That’s what it meant to me.”*

Closely related to not identifying there was a mental health issue, was not seeing symptoms as warning signs. For example, one participant spoke of being in denial that they needed help until they were forced into treatment. They further disclosed that they did not understand why no one stepped in and offered them help until their situation had become extreme:

*“I really related to that denial and I didn’t get help until I was pushed into it from losing my daughter and they were like ‘you need help’. Until the shit hit the fan, until I was completely broken and had absolutely no-one – that’s when I got help.... Why do I have to be so broken to see the warning signs myself, you know. I guess the people I had around me, they didn’t care either. I think that’s a huge issue with the system. You’ve got to be on our knees, completely broken until someone will give you help.”*

Another participant spoke of how the general lack of community conversation around problematic drug use meant they did not have a frame of reference for their problems:

*“The conversation isn’t open enough or broad enough for people who have been exposed to it to say - to check and say “this looks like something I’m experiencing right now”. It was completely unknown to me what addiction might even look like.”*

For another participant, their personal history dictated that they identified with an AOD issue, rather than a mental health issue:

*“Yes, I took a lot longer to admit I had a problem with mental health than what I did with drug addiction, because it was staring me in the face and my father had been an alcoholic and we’d been involved in [name of service supplied] because of family and all kinds of stuff, that wasn’t quite as hard. Admitting I needed support for mental health problems – I just kept saying ‘no, I don’t need it. Somebody else does.’”*

Some participants noted that accessing AOD treatment did not necessarily mean that mental health issues were also going to be recognised. For example, one participant stated that the type of support they had initially received within the AOD sector didn't help them identify that they had mental health issues. They'd been an attendee at a self-help group which at the time did not discuss mental health issues, so it did not occur to them to frame their issues in this way:

*"[Name supplied] didn't talk about mental health as such. There is a growing awareness within the groups of drug issues, but they still don't look at the reasons why somebody drinks or takes drugs. There's virtually no discussion about it at all. So, I never thought to look at it, it never crossed my mind."*

This statement highlights one of the issues of mental health and AOD issues being seen as separate from each other. Service users who access only one sector may not develop an holistic understanding of their problems.

The above participants' comments point towards the problem of a general lack of understanding of what the range of a mental health or an AOD issue encompasses and, perhaps more importantly, that people do not need to be in an extreme crisis before they can access treatment. It further reinforces the notion that 'keeping things hidden' fails to normalise the issues people face and, in turn, people are unable to learn from others what constitutes a problem.

### **Structural barriers**

***"...the point I want to put across is lack of information. I didn't know I could go to rehab on Centrelink. I thought it was just for rich people."***

A number of structural barriers to treatment were identified. The issues of how people find out about services, their treatment options, accessibility and affordability was raised. The discussion supports the experiences discussed by the participants of the 2016 focus group in which awareness of available services was also raised as a significant barrier to treatment (MHC, 2016).

Lack of information around what help was available was cited as a reason for not accessing help. The lack of information presents as a combination of not knowing what to access, where to access it, and the what types of supplementary supports are available. This is articulated in the following quote:

*"I always felt like trying to find the right mental health person or service to engage with was much like trying to find a needle in a haystack. We're not taught – much like if you find yourself in trouble with the police and you suddenly need a lawyer, how the hell do you pick the right one? Nobody tells you 'look for this, look for that, ask this question, ask that question' and it's so easy as a human being to just certainly not click with someone or to feel stigma or misunderstood or somebody specialises in an area and they want to apply it to you and [what] if it doesn't apply, you know?"*

Another participant stated that the information provided by their general practitioner (GP) was insufficient:

*“...the information that I received was very like, text book and [the GP] gave me a print out and like that went straight into the bin. You know, I needed something a bit more.”*

This quote indicates that, for some people at least, simply handing over printouts or other materials may not be sufficient to facilitate people seeking services. Some people may be incapable of following through due to their current vulnerabilities. This was illuminated by another participant who was given a pamphlet by a health care professional:

*“Yeah, like I wasn’t capable of calling up those numbers or making that sort of referral process happen.... because I had a lot of anxiety around – and just getting in there in the first place was hard enough for me at that time.”*

Some participants felt that, due to staff shortages and lack of funding in the public sector, there was a dearth of quality care for people with complex needs. However, the cost of accessing support in the private sector was seen as prohibitive by many of the participants. This is encapsulated by the following quote:

*“I think another thing is cost, isn’t it? Cost is a big thing. When I was working and could go and see a psychiatrist or something, it was \$140 an hour, but now because I’ve seen financial hardship for years now and ... the quality is different ... because I found with \$140 an hour it’s more relaxed ... you know, they had a nice room, it was relaxing, and they were really into listening. Whereas you go [elsewhere] and they’re understaffed and underpaid and that sort of thing. You can’t relax, you’ve got to get through all of these other things. So, there is the difference.”*

The presence of waitlists was seen as another barrier to treatment engagement by participants across all of the focus groups. The problem of waitlists was raised as, not just an inconvenience, but something that was deleterious to change momentum. Many of the participants felt that the current system did not capitalise on momentum. Steps to get help are often made when issues are coming to a head and motivation to make changes is high. Being told at this stage that there is a wait to get into treatment can lead to a sense of having hopes dashed, as one participant articulated:

*“Also, it’s around capitalising on momentum. When someone’s got a problem and something’s really gone down, there’s this sudden period of – a huge amount of ‘right, I’ve got to do something right now. This is bad.’ So, there’s this momentum – and then you encounter admin, front desk, waitlists – forget it. It’s all over, you’ve lost me in a couple of days if it’s not addressed now so it’s that momentum where you jump – your eyes are open, you’re really in that need, if you’re not met there, you’re off again. So, it’s capitalising on that momentum in people’s experiences when they’re in crisis.”*

One of the participants raised the issue that motivation for treatment does not stay high; rather, it will ebb and flow and a service may contact a waitlisted client when their motivation to change is starting to wane. This presents another issue with waitlists:

*“I think with waiting periods and timeframes and that with treatment centres and so forth, if you are ready to stop when you ring up that service and say ‘right, this is rock bottom, I need help’ [and you get] ‘no worries, we’ll have something in three months’. No one is really going to be at the same spot in three months and vice versa. Like [another participant] said, they might ring you up and you’re not really ready so – I mean, bed spaces at residential places and stuff like that are obviously a massive issue.”*

One of the participants, who is currently employed as a peer worker, described witnessing the impact of waitlists on service users’ change momentum:

*“We have it constantly at work where people come in and they want to, you know, get into different programs, and they wait. So, it’s like, you know, ‘I might as well go back to using then.’ They’ve only that little, small window of opportunity and if you have to wait too long, people are like, ‘well, stuff it, I’ll just go back to using.”*

These concerns echoed those that were raised in the 2016 focus group, in which participants disclosed they felt particularly vulnerable when waitlisted for treatment (MHC, 2016).

Many of the participants identified there were often other obligations that served as barriers to accessing help. One participant, for example, described how their obligations, as a recipient of Centrelink benefits, impacted on the time they had available to seek support:

*“I was working, I had limited petrol in my car, I wasn’t having after-school care for the older children, I had to make sure I was home by 3.00pm for my children. You know, going to services and finding the support and help takes a lot of time and effort – not just the travelling to and from, but the time spent and you might need... one service cannot meet your whole entire needs. You might need a few supports and the way the welfare system is structured, it’s either all or nothing – you’re either on Newstart, but if you’ve got significant trauma, but you don’t meet the criteria for like... you can have a mental health diagnosis – depression is not going to get you on a DSP [Disability Support Pension], but bipolar is, and let me tell you, I wish I never had that diagnosis of bipolar. So, the thing is, if you’re on Newstart, most of the time you have to spend actively looking for work or you’re going to get punished so you’re vulnerable and there’s other stuff that comes with that. So if you’re someone who’s in that situation or has to have a job and you’re really struggling with life, where do you fit in the time to be able to get the support you need so you can reach your latent potential or optimal wellbeing?”*

These comments provide some insight into how a system that is, in principle, designed to help, can sometimes actively interfere with individuals’ capacity to initiate engagement, and then fully engage with recovery-oriented services.

## **Factors influencing sector pathways**

***“... and it tends to be whichever aspect of your life that gets out of control faster.”***

It appeared that many of the participants first entered services not through informed choice but rather through whatever issue was most prominent at the time. For example, one participant identified that, for them, the reason their treatment pathway began in the AOD sector was that factors associated with their AOD use brought them to the attention of services, and this subsequently influenced referral options:

*“And to answer your question, I think that’s why you access AOD first – I think that’s probably the first – especially for our generation – your mental health wasn’t as well recognised so the presenting symptom would be drug use or violence or crime or whatever that came with that lifestyle or whatever came with it. So, then you’re referred on to an AOD place, rather than a mental health place.”*

In contrast, one participant disclosed that when they had become obviously psychotic, this ‘forced’ them into the mental health sector:

*“I probably didn’t engage in AOD services because I was forced into the mental health system because behaviours were quite psychotic and the people around me were like ‘Ah! You’re crazy!’ So it was kind of – the outward play of what was going on in my head showed signs of that psychosis. But you know, like, how the systems are set up, pushed me there.”*

This participant further disclosed that this was despite the fact that their first three admissions were from drug-induced psychosis.

For others who had not engaged in both sectors, despite having co-occurring AOD and mental health issues, a number of them identified their primary reason for not accessing both sectors was that all of their needs had been met by the one sector. For example, one participant disclosed that their GP and AOD counsellor work in collaboration with them around their mental health and AOD use and this is sufficient for them:

*“... with my GP and the clinician I see at [name supplied]. We’ve touched on my anxiety and also with my night terrors I sometimes get. I’ve been able to wake myself and talk myself down and tell myself what’s logical and what’s not. So when I’d wake up and think my ex-partner had taken my daughter and I can’t get back to sleep, and I have to check the house over, it’s hard but I know that I’ve got to talk myself down. It’s good that I’ve got that relationship with the person I see at [name supplied] and that does help with my mental health needs.”*

Another participant stated that they didn’t feel that they ever properly engaged in mental health services because they felt the options were better for them in the AOD sector. They stated they preferred treatment that was oriented towards behaviour-based therapies rather than prescribed medications:

*“I don’t even know whether I’ve properly engaged in mental health, like I’ve seen psychologists and counsellors. Does that count because I went to them presenting with, like I said, anxiety and depression? I’ve seen a psychiatrist, but my experience, apart from one psychologist who I did CBT with – the rest just wanted to throw medication at me and I didn’t want to go down that path. So, that was my experience and nothing really worked for me until I went into residential drug and alcohol treatment.”*

In summary, most discussion on the topic implied that people often did not have a great deal of control over how they initially accessed treatment, nor which sector they accessed first. It was often dependent on which issue became problematic enough to garner attention. This makes sense when viewed in the context of previous discussion around stigma and personal conceptualisation of issues, i.e. if people feel underserving of treatment or do not have a concept that they have problems that can be eased by seeking support, they are likely to access treatment only when their problems have compounded and are harder to conceal from others.

## **2. Participants’ experiences of the roles services have played in their recovery**

The questions asked in this section of the focus groups were designed to explore what service aspects supported and facilitated or hindered recovery. Participants were asked:

- As a person with a lived-experience of AOD and mental health issues, tell us about your experience of being a client in mental health-specific services?
- What were the things that helped? Why?
- What were the things that didn’t help? Why?
- As a person with a lived-experience of AOD and mental health issues, tell us about your experience of being a client in the AOD-specific services?
- What were the things that helped? Why?
- What were the things that didn’t help? Why?

The questions were intended to elicit responses describing experiences as a client in the AOD and mental health sectors separately. However, during the focus groups the themes were discussed as a whole, perhaps because people with co-occurring AOD and mental health issues do not necessarily see them as separate. As such, they will be reported in this way. Again, a number of themes were identified and will be discussed.

### **Peer support**

***“... lived-experience does need to be recognised as an authority in this space.”***

The value in peer support for individuals’ recovery was noted across all focus groups. Again, this aligns with the experiences of the 2016 focus group, in which the participants cited peer support as being one of the essential elements of their recovery process (MHC, 2016). Peer support is defined as “... any organised support provided by, and for, people with similar conditions, problems or experiences” (O’Hagan, 2011, p.5.). Within services, this can be in the form of support groups, or peers working either as paid staff or as volunteers.

One of the participants spoke generally about why people with lived-experiences should be seen as an asset to the mental health and AOD sectors, not least because they are the people who have the best understanding of what works currently:

*“People who have life experience in that field you want to grow in, those people should be valued and treasured or seen as a valuable resource to the field. They are really the only thing you’ve got in society that can give you an indication of what can work in the modern world.”*

Engaging therapeutically with someone who has a lived-experience of AOD and/or mental health issues was viewed as important for feeling understood. This is encapsulated in the following quote:

*“Conversations. When you share your real, in depth what’s going on – sometimes in those service providers you get, ‘aw, poor you,’ - I got it in church as well, ‘poor you.’ When you get – you share that with someone who has been there and they say ‘me too’ and they jump in the hole with you and they say ‘let’s go. I’ve been there before. I’ll help you.’”*

It was noted that services appeared to be embracing the idea of having peer support workers as part of their service. For example, one of the participants spoke of their experience of being included in important processes:

*“My experience is actually quite a good one because we’ve just had our – it’s not an assessment – accreditation process and we were given a voice with the accreditors...”*

There were, however, some participants who disclosed costs to working as a peer in a professional environment. One participant articulated this by sharing their experience of feeling as if they were losing the peer aspect of their identity in this space:

*“When you step over the threshold into the professional side of things, it’s almost like you’ve got to re-stigmatise yourself a little bit to step away from your lived-experience because you’re a professional now and it’s expected that – you don’t talk about that stuff anymore because you can’t be the face of an organisation if you’ve had that past.”*

There were also some issues raised with the management of the peer workforce. One participant had particular concerns:

*“I’m not very impressed with the ‘peer space’ because a lot of the ‘peers’ who call themselves ‘peer workers’ who got there through doing this certificate 4 in mental health workers, they’re the absolute experts and they’re not the experts in my lived-experience... I’ve found it’s a space of bullying, absolute bullying and people who have this cert 4 in mental health peer work, and... are now sitting in these very powerful positions in these workplaces that are extremely inappropriate... A lot of these peer people come from a place of ego, and when you do that it undermines the philosophy and principles of peer work: sharing, respect, mutuality, creative*



*collaboration... people are not getting their needs met from this group because that person who started that group is, 'it's mine, mine, mine.' So then they go and set up another and it's the same, and it's the same and it's like, you really have to be careful in a peer space too because you're not a psychologist, but you can go and facilitate a support group – I can go and facilitate a support group, but the fact is I'm not a counsellor or a psychologist. I can't bring up something that is going to cause someone extreme trauma because I can't leave them like that, because I don't have the skills in an hour to work it out and some of these people come in with very high expectations that we're going to wave a magic wand and fix things.”*

Whilst this quote represents one participant's experience, it still serves as a timely reminder that structures and support are necessary for consumers who do decide to become peer workers. Peer support has been around for a long time, and its value is widely acknowledged. However, peer workers will still require adequate training, guidance, support and supervision, just as any other worker would, to ensure safety for all.

The above discussion adds to the body of literature that acknowledges not only the valuable role peers can play in the recovery of others, but also the valuable role peer work can have in helping people who have had significant issues re-enter the workforce.

### **Autonomy and choice**

***“... because once you get into trying to control people or influence people in a deliberate way and it doesn't work, it just gets worse.”***

The notion of choice and autonomy being central to peoples' perception of 'doing better' in their lives was seen as essential for any kind of recovery. An important component of this that was identified was when service users had the sense that they were afforded the autonomy to decide for themselves what the focus of treatment was, their outcomes tended to be better. For example, one of the participants shared how their experience of choice and autonomy shaped what helped them:

*“Lots of things helped along the way, but the ability to make my own decision and not have someone else – you know [make the decisions], for me – to go into [name supplied] and have been told that 'we're not going to tell you what you are, you decide for yourself' – it's like, 'if you want a drink, go and drink, but if you want to learn how to live a decent life, you can do this'.”*

There was discussion on the difference in treatment outcomes when services allowed the service user to decide which concern (AOD use or mental health) got addressed and when. For example, one participant shared that they had recognised that their mental health needed to be stabilised before their alcohol use could be addressed:

*“So, I started to look at my mental health way before I could look at my alcoholism because it was too – I could worry about – I could focus, straighten myself, on all these other things before I got to the core problem and then I had other tools in place to start looking at my alcoholism.”*

The treatment service that this participant was engaged with at the time structured treatment according to their wishes, even whilst being aware this person was also having issues with alcohol. Not only did this foster a sense of autonomy, it also helped provide the tools for tackling the alcohol problem:

*“So, I actually did a 12-step mental health program where I could start focusing on tools for my mental health and they were well aware that I had an alcohol problem. So that introduced me to 12-steps to get the tools.”*

Participants in a couple of the focus groups discussed their experiences of not being referred to services of their choosing. This was viewed as an aspect of service delivery that was unhelpful because they did not think that individual circumstances and preferences were taken into account. For example, one participant was told by a mental health professional that they were being referred to a certain community-based service. They had tried to explain that they'd had an unhelpful previous experience at that service. However, their referrer gave no alternatives:

*“I was told what to do: ‘You will go to [name supplied]’. Like I said, I don’t particularly like [name supplied] and I wasn’t given any alternatives.”*

This issue is further compounded when a specific treatment need isn't able to be met by the service within a consumer's catchment. For example, one participant told of being sent to a mental health service in their area, only to be told that this service didn't treat the issue they'd been referred for. Furthermore, there did not appear to be a provision whereby they could be referred to a service that treated their presenting issue:

*“... due to these and coexisting AOD things and that, you might be itinerant or couch surfing or whatever you might be, and you go to [name supplied] and they say, ‘nah, you’re not [eligible] here because your postcode is somewhere else and you can go all around the place. It’s very difficult to find help with that. It was always a jurisdictional drama. And recently I was re-referred back there for ADHD and they said, ‘no, we don’t treat that’. I found that to be another barrier...”*

Not all experiences were negative. For example, for one participant having autonomy to choose whether to take medication was seen as beneficial:

*“I chose not to be on medication and do you know what? Since I’ve implemented a change in diet and exercise, connections with healthy people, learning how to identify healthy people and learning how to say ‘no’ and put myself first, I actually don’t need medication...”*

Related to choice and autonomy around services is the autonomy to define issues and needs in one's own terms. This can be seen as an expression of the fundamental human need for self-determination and is an important consideration for service delivery because, often, AOD use is a management strategy for mental and emotional distress, as articulated here:

*“I think alcohol and drugs were never the problem, they were the solution. That was a solution I was using because this was always a problem, like the mental – yeah. Taking those substances actually helped me deal with it.”*

And:

*“I couldn’t address my mental health issues until I stopped using and I couldn’t stop using until I had a safe space to do that. So, these things needed to be in place. It’s like the chicken and the egg, but that was certainly my path to recovery.”*

One of the participants expanded on this by discussing self-medicating in the context of people making informed choices:

*“I think the intelligence in self-medication is undervalued by society in a big establishment picture. I am always reluctant to pass judgement on anyone who is self-medicating, even if they’re drugs that I disapprove of or think are dangerous like speed. I prefer to withhold judgement because I think generally if people, especially the people I’m mixing with who are senior citizens of the drug world, if you’re using drugs seriously after you’re 35-40, then there is probably some serious intelligence or drive at work here and it can’t just be dismissed or cast away. Like you said [referring to another participant], the side effects to psych drugs and the side effect to lots of drugs. Coffee, you can’t sleep and cigarettes you get sick and alcohol you go and run over people. I think – look, I’ll just put it out there. I think heroin gets bad press, I am a big supporter of it, but in the bigger picture I think there is intelligence – I’ve seen some terribly messed up people from horrible childhoods and marriages and legal problems and violence and stuff who have ended up homeless, living on drugs and I would hate to think what they would have been like, some of them, without that comfort because they were messed up people. I’ve seen people ten years down the track who, oh surprise, surprise, they didn’t die of consumption or whatever. Somehow or other they’ve got a [name supplied] flat and they’ve got a pet dog and they’re alive and managing their life somehow or other.”*

The above quotes represent the importance of affording people the right to self-determine without judgement. They highlight the need for workers to understand how their clients view their issues, given that some clients may view their AOD use as a solution to a problem. Indeed, as the previous quote alludes, some people may use AOD to help manage trauma symptoms. Focussing treatment on the AOD use only, particularly if this is not how the client frames their problems, can result in a missed opportunity to support change in other areas of a client’s life. For example, one of the participants spoke of services having too narrow a focus on treatment goals:

*“Their focus was on your drug use – reduction of your problematic drug use. That to me was not appealing, I was happy in my destruction, as happy as you can be. No one ever bothered to pick up the other things in my life that were going to be helpful.”*

People can feel disempowered if they are not afforded the autonomy and choice to contribute to the discussion around their treatment. For example, many of the participants

described how they felt disempowered because they felt they had no 'voice' in their experience. For example:

*"... in the mental health system, for me, I was disempowered. They gave me a label, I was locked up, needle in the bum, 'you have to take this because this is what you need to get yourself well'."*

And:

*"...so, I handed my will and my life over to the care of the mental health profession and they said, "you fit this box" and I said 'ok'."*

Another participant disclosed that they felt the broader welfare system contributed to disempowerment because the way it is structured can make it easy for people to be given a label that can stay on their records:

*"I had a job capacity assessment at Centrelink with a woman who – I'm sure she was great at her job, but I don't know what her qualifications were. I sat with her for less than half an hour and explained what my symptoms were from my drug use and my lifestyle and she gave me a diagnosis of bipolar and I went onto disability payments through Centrelink. That's still on my record. I'm not bipolar..."*

Systemic changes can impact choice and autonomy around treatment focus. One of the participants noted:

*"I think there needs to be a discussion around the welfare system as well, because mental health and AOD, whether they're considered separate or not, they're both massive welfare concerns as well. I think the change that came in in July has thrown the cat amongst the pigeons with no longer being able to present with a drug addiction or alcohol addiction as a reason for not working anymore. I know people in my life who have since gone to their GP and they were getting medical certificates for alcohol and other drugs. Now they're going for anxiety or post-traumatic stress. So that's forced them into the mental health sector."*

From the discussions highlighted, it is apparent that affording people the autonomy to define their issues in their own terms as well as giving choice in service and treatment type is seen as a significant positive in people's recovery journey. However, also from the discussions, it appears that the system is not always structured to facilitate this.

### **Service aspects**

***"I needed more than just a one-hour session with somebody once every month or so."***

There was much discussion on the attributes of services that either facilitated or hindered recovery. A couple of the participants raised that some services appeared to have policies that were experienced as punitive:

*"I mean I'm not saying I didn't have help, but the help I had was very punitive. You know, if I missed an appointment, they'd cancel it..."*

And:

*“And I think if you really hit the trifecta, which a lot of people do, of having both physical, mental health and alcohol and other drug issues, and depending on which of those you end up being – there’s almost a punitive response from some nurses when you’re being treated for a physical problem, and it can be something massive, but they’ll hold back on the painkillers...”*

Communication was considered important. One of the participants described how they were placed in a residential institution, but not given information about why:

*“But also those people who diagnosed me and put me in [name supplied] didn’t tell me why I was there and I had to ask after I’d come out what was my diagnosis.”*

Another participant discussed the impact some service requirements had on them:

*“I’ve had to make up names and phone numbers to put down because I’ve been so pressured into this, where I wasn’t going to be able to access a service unless I was able to fill out supporters or next-of-kin. And there were no supporters and no next-of-kin and so I just had to make up these humans and remember who they were and what my basic description of them was. It’s humiliating. But it’s just absurd that it’s got to the level where I have to have fictitious characters.”*

The need for services to be able to facilitate client-specific needs was raised:

*“And for me to start off with, I needed a male counsellor. That was a big thing because I just didn’t have that trust in females at that time.”*

Further to this, participants described unhelpful outcomes if workers do not consider the impact of some dynamics in therapeutic groups, for example, mixing voluntary and mandated clients in groups. One participant pointed out the impact of this on them:

*“... the irony was I went with the best of intentions because I went to one of the... groups and it was the most demoralising experience I could possibly have had because the people that were there were there saying things like “the court says I have to be here for such and such a time, but I’ve got to leave early so I’ll be here for half an hour” and then there would be another one saying “I’ve got to attend a certain number of sessions so I can get my kids back” and I walked out of that session thinking ‘oh my god, I actually walked in wanting help, I was trying to genuinely get better and these are people just trying to use the system’. I was so demoralised that that’s the only time I’ve used a government system other than when I was brought in by ambulance...”*

One of the participants, who now works in mental health discussed how funding bodies’ reporting requirements to can impact an agency’s or worker’s capacity to engage meaningfully with clients:

*“...because every six months you’ve got to have all the files redone, you have audits, you have people coming in and checking that every bit of paperwork is correct and*

*you've got to have a certain amount of people in a certain amount of time and get all your numbers right. Instead of actually sitting down with someone and just getting to know them, having a conversation about what they really want, it really is, 'right, we've got to get this done with you in this time' and it becomes very much outcomes-based and what we can show on bits of paper. I noticed that when I was still seeing services. I felt that and now I know why."*

From the above discussion, it appears that there are some service aspects in the form of policies and procedures that impact how a worker is able to fulfil their role, which in turn influences the client/worker relationship.

### ***Relationship with workers***

***"Also in the mental health system... I actually had a nurse who gave a shit about me. A mental health nurse who came out into the community and I just knew he cared..."***

Consistent across all focus groups was that the most helpful aspect of treatment, whether in the AOD or mental health sectors, was being communicated to that they were cared for by their worker/s. This largely took the form of feeling valued as people by their workers, however it also resulted from workers conducting regular home visits; the sense service users got that they were being listened to; workers across different services communicating with each other; and workers being transparent with their clients about the information they have shared with other workers.

There was much discussion about the importance of feeling that workers valued them as people. This was often identified as the difference between successful and unsuccessful outcomes. For example:

*"People that invested in my life, people who hitched their wagon to my experience at whatever level and made me reflect on myself through them. They gave a depth and meaning to my life because, in whatever way, they cared."*

And:

*"I've had the experience of a worker from an organisation who took care of me and it was a profound experience because you had those attitudes of – and I felt like I was cared about. She cared about what the outcome was going to be for me. I think when people are suffering from serious depression; it's probably all they need."*

One of the participants shared their experience of a caring GP:

*"... he rang up because – he said, 'it doesn't sound like you're going too well, I'm just checking in to make sure you're ok'. That's beyond what a GP would normally do."*

Another participant shared their experience of being afforded the time to build a trusting relationship with their GP:

*"And the other thing that I'd like to say is that I'm lucky in the fact that I've been seeing the same GP for 17 years now..."*

This quote highlights the importance of relationships between workers and their clients/patients across all aspects of service delivery – not just counselling relationships.

A number of participants identified being visited in their own home by workers as a contributing factor to feeling 'cared for'. For example, one of the participants noted that workers taking the time to do home visits made a difference to their treatment outcomes:

*"I actually had a psychiatrist who I still can't believe to this day. She came to me [at my house] and sat in my lounge room for an hour and chatted with me and she did that twice. And the nurse came and saw me every fortnight for 6 months. They listened to me; they really did listen. I said, 'look I'm not happy with these happy pills...' She said they'd reduce the dose and work with me on it, and I can't speak highly enough of them."*

Another participant spoke of the therapeutic value of a simple connection:

*"I had a [name supplied] caseworker for a while and I honestly can't even remember – I don't think I would have gone to them presenting as AOD, I would have gone to them presenting as [an] isolated, anxious person and all they did was come out once a week and have a chat to me. I managed to get over six months clean just with that"*

And another:

*"Yes, they visited me and learned a little about me, which no other public hospital has ever done..."*

Belief and time were cited as important factors that the worker communicated to clients that made a difference:

*"Someone who believes in you and wants to work with you to help you – someone that you have confidence in that was going to help you and walk alongside you in your own road to recovery, that's what you need."*

And:

*"... the most valuable thing you can give someone is just your time. Because they want to talk, they want to be heard..."*

Acceptance and lack of judgement on the behalf of workers was also seen as making a difference:

*"The turnaround was when I went to uni and I had a really fantastic lecturer for AOD who was also a counsellor and I felt – she was so open and accepting and everything, I felt so safe to talk to her about the issues I had with alcohol. She then told me about her agency and yeah – that was definitely a watershed moment. "*

There was discussion across all of the focus groups around being afforded the time to develop a trusting relationship with your worker as being a central aspect of 'what worked'. It was generally agreed that this was important because it communicated to them that the

worker cared enough to allow the time and that the client was the one who was setting the agenda for outcomes.

These observations were in contrast to the impact that the feeling that workers did not care had on participants' experience of treatment. This was described as being further compounded by the aforementioned impact of stigma that had been experienced and internalised. For example, some participants raised that there was a sense that services didn't bother with you if they thought you were a 'lost drug addict'. A few noted that they felt judged as a 'hopeless case', and there was a sense that if you were a 'hopeless case' you were considered a bad investment, particularly if you were seen as a 'recidivist drug user'. For example, one participant stated:

*"A lot of people turn you away as well. They don't want to be helping you anymore because they just think, you know, they give up on helping."*

These thoughts were shared by another participant:

*"I think because I was obviously such a recidivist drug user, I wasn't worth the effort in the referral work or case management work or any of that. I was just going to end up back in the criminal justice system; they'd sort me out there, which they never did of course..."*

Another participant articulated that they felt that part of the reason workers would give up on them was because for a long time they did not understand what was involved in the treatment process. Over the years they had attended services with an expectation that the services would somehow 'fix' them. By the time they understood that they had a role in the therapeutic process and was ready and willing to embrace it, they felt that workers they engaged with lost any expectation that they would change:

*"I think – I know for me, for a long time when I was seeking services I wasn't necessarily at a point where I was 100% working hard on my recovery. There was a part of me that really thought that somehow they would do something for me and that would change me and my life would somehow get better. By the time I was ready to put everything into it I feel like a lot of [workers in] services had sort of given up and felt that 'she's never going to change'."*

Another participant with a similar experience described the consequence of feeling as if they'd been given up on:

*"So you pull back in. And all the positiveness and optimism goes down."*

These quotes highlight that a worker's conveyed beliefs about a client's ability to change can impact on a client's feeling of hope and optimism about their own recovery. They also illuminate how a mismatch between clients' and workers' understanding of processes might negatively impact the relationship between the client and the worker.

Furthermore, a negative experience with a worker can derail treatment seeking:



*“I had a psychologist change his mind about wanting to take me on as a patient half way through our first session and I thought that was awful and that put me off – that was the last time I tried to seek help really. Because I’d been referred to him through a drug service, I think he’d expected me to be drug free at that point, but I’d switched over from opiates to meth use and, you know, I wasn’t using all that often, but I was still using. I don’t know ...And he said [inaudible] about my meth attitude and he was asking me for an emotional response. I laughed and said “I thought it was a piece of junk” and that offended him. And that along with my ‘meth attitude’ – he said “Oh actually, I’m retiring so I won’t be able to take you on”. He gave me a stack of photocopies that big [indicates] of other doctors that I might choose and for years after that I drove past his office and his name was still there on the door. He hadn’t retired; he’d just changed his mind. Rejected.”*

Workers who communicated caring were generally considered to be working in partnership with their clients, as opposed to ones who facilitated an ‘expert-recipient’ relationship with their clients:

*“... like ‘ok, you’re not ok, I’m here to fix you’ or ‘I’m here because you’re not ok’. It’s like ‘we’ll medicate you’ or whatever that is – it’s like a – here’s an assumed or inherent ‘better than’...”*

There was a sense that workers who communicated empathy were considered to be more helpful. This is illustrated in the following quote:

*“... One of the nurses who was on placement I think, he was very, very helpful. Very empathic. He alone probably did more good than anyone else in there...”*

The same participant described a contrasting experience from a different worker within the same treatment episode:

*“The psychiatrist I never took a liking to, ‘you will do this’ ... it wasn’t a matter of ‘how do you see yourself?’ or ‘what can we do?’ there was none of that. I wasn’t included, I was told what to do.”*

Whether workers communicated dedication to their work was also cited as making a difference:

*“I also want to say that I know that in AOD and mental health some people love their job and some people don’t and I think that’s a huge difference as to whether you are just a box to tick or ‘I actually give a fuck about you’.”*

That this had such a significant impact on so many of the participants may offer pause for thought from workers. What is being communicated, verbally and non-verbally, is central to the therapeutic alliance, and thus, outcomes. Furthermore, as one participant noted, workers who did ‘go the extra yard’ may have more fulfilling work lives:

*“I’m saying that patients in the mental health world are individuals and some of the most vulnerable individuals and it should be something special to be dealing with them, because the feedback I got from people - not necessarily people who were treating me or whatever - but people that were involved in various fields, was they*

*found – you know, the ones who gave the extra yard for their patients – they found it interesting and rewarding dealing with this and gratifying to see people develop and grow and overcome things and find themselves.”*

Relationships between workers were also considered important. This refers to the workers in a service user’s life working with each other to support the client and being transparent with the client about how they are working together. This was raised as an important issue regarding the development of trust in the therapeutic relationship. For example:

*“Trust is really good and having a good relationship. I’ve got a good relationship with my GP and my clinician and there’s really good trust going on between [name supplied] and [name supplied].”*

And:

*“I found when she was working with my other Housing Support Officer from [name supplied] ... those two would correspond with each other really well and that was really helpful for my situation. So those guys worked hand-in-hand.”*

Furthermore, it was noted that when workers communicated well, their client’s lives got better:

*“I know that when I’ve got my support with the services, when those guys are working well together my life is a lot easier in a way, you know. It does help and like you said, communication does help.”*

Transparency was considered important:

*“I’m not there when those guys are talking, but I know the conversation is about me and usually they will ...contact me and I will know about what was said.”*

Closely related is the concern about who has control over, and access to, your personal information. One participant, who had accessed the mental health sector, disclosed they felt they had no choice around ticking the box that enabled their service to release their information:

*“... because when you go in you have to tick the consent for information to be shared.”*

And

*“... I had an incident of something and when I needed to go and get a mental health assessment I called up the [name supplied] to see where I’d go for a mental health assessment and they already knew all of that information.”*

However, another participant, who had accessed the AOD sector, cited that they have had a different experience with this:

*“My experience was this: any time they wanted to contact someone else they let me know if they were going to share my information, and got me to sign a form authorising... it was certainly expressed to me that that was my choice...”*

The comments cited above serve as a reminder that workers' respect for a client's right to keep their records confidential is important for their clients. Additionally, transparency with the client about what information is shared between services can increase trust and a sense of choice and control.

### **Staff turnover**

***"...that continuity of having the same people, staff not coming and going and all that sort of thing, you know."***

Staff turnover was consistently cited as a source of frustration amongst the participants in all focus groups. Not only was this seen as frustrating, it was also viewed as detrimental to change motivation. One participant illustrated this in the following quote:

*"Well that's what I find because I go to see one and then there was another one and another until there were all these different people and you've got to repeat yourself and repeat yourself. The whole story over and over again and by the end you just go 'you know what, let's not do this. Just don't worry about it'."*

Another participant described their experiences:

*"I'm now engaged with [name supplied] – I was actually engaged with them about four years ago. Saw one counsellor; she was gone in eight weeks. I had to go and see another counsellor; he was gone in eight weeks. So, starting from A going through to Z, every single time – I got totally pissed off."*

The following exchange occurred between two participants:

Participant 1: *"...that retelling of your story over and over with eight weeks one counsellor gone then another eight weeks another one gone again, it's like, 'oh, here we go again."*

Participant 2: *"It's like why don't you just write my life in a CV and just pass it out."*

Participant 1: *"Exactly right. I might as well just go and write 20 pages and say 'right, there you go, that's my list. That's what's wrong with me, how're you going to get me through this, what are we going to do to sort it out? They didn't give a shit."*

A couple of the participants disclosed that they had found their own ways of managing this. For example, the above exchange was followed with another participant sharing how he managed staff turnover by asserting his needs from the outset:

*"I'm now going to a counsellor, who I've been seeing for the last 18 months. When I first started seeing him I said, 'This is the first question: If you're going to be going within 3 to 6 months we need to bring in the new counsellor for the last two sessions because I'm not going through all of the bullshit again to the next person.'"*

### **Siloed services**

***"One of the things I find there is a gap. Sometimes they don't see the mental health and addiction together."***

The issue of siloed services was seen as a barrier to treatment across all of the focus groups. The term 'silo' in an organisational context refers to "... organisational units where there is a breakdown in communication, co-operation and co-ordination with external parties" (Fenwick, Seville & Brunsdon, 2009, p.ii.). 'Siloing' can occur within and between organisations.

There was consensus from participants that mental health and AOD services being separate from each other enabled a silo mentality to develop between the two sectors and this led to service users receiving support from services that were not necessarily well equipped to manage people with co-occurring issues. Indeed, many of the participants stated they sometimes felt they were forced to address issues they weren't ready to address. For example, there was a sense that the mental health sector had an expectation that people within their service should be addressing their AOD use and that their access to treatment in the mental health sector was contingent on whether they did this. It was felt by some that this approach did not take into account the role AOD use was playing in mental health symptom management. One of the participants articulated this problem:

*"So it's like, I've got a drug problem because like, that's my solution because my head's my problem, but I'm like, taking in these drugs to help me deal with my head..."*

Furthermore, some of the participants felt that their mental health wasn't asked about if their presentation at a service concerned their AOD use:

*"I was in there for a week. Then they said 'you can go home now'. I said 'why? I'm not mentally stable. [They replied] 'Yes you are'. I said 'no – you're not looking at the bigger picture here. You're looking at the alcohol, not the mental health [issues]."*

This participant went on describe what happened a week later:

*"... So then [name supplied] rings me up and asked me how I was going. I said 'I'm up the shit' and they asked me what they could do about it. I told them 'what you should be doing is getting me back into [mental health ward] and sorting out the mental health issues."*

Another participant described trying to get help for a family member:

*"... we just kept on telling the clinician 'could you just get some help for him for the alcohol and other drug treatment'; they say, 'we only take care of the mental health issues.' You're on your own, It's almost like that."*

Another described their experience:

*"Because at the moment with a lot of mental health services, you can't continue going there if you've got an alcohol and drug problem. They won't take you."*

It was further felt by the majority of participants that the current practices of separate sectors tended to diminish the relationship their mental health or AOD issue had with the other

aspects of their lives. The following quote raises the point that underneath mental health and AOD issues is often suffering:

*“We shouldn’t think about it as mental health or AOD or whatever. It’s just an industry for people who are looking for help.”*

One of the focus groups discussed siloed services more broadly. Some participants noted that it was an issue that was not contained to the AOD and mental health sectors and that this does not get talked about. For example, one participant stated:

*“And this is part of the silo problem. You’ve got a child that doesn’t sleep, you’ve got mental health issues, but you can’t go to [name supplied] because you’ve got this issue, and ‘we’re sorry, but we don’t help with that’.”*

Another participant expanded upon this point:

*“I think what we’ve talked about with the education, and you’re doing this with the AOD and mental health, kind of joining them together, but I get a bit irritated when we talk about de-siloing, but only talking about two of the siloes... you know, because there’s also housing, there’s also domestic violence, there is family issues, there is social issues, there’s education – in all of the areas in our macro system, they are all siloed which takes away the individual person’s holistic experience of living.”*

This is further highlighted by a related discussion on the potential benefits of structuring services to be more holistic across all areas of a person’s life:

*“... treatment that doesn’t focus primarily on your problematic drug use. You can focus on either social inclusion or value other activities that you’re going to pick up that are going to have the effect of dropping your drug and alcohol use.”*

And:

*“The other thing that’s not readily accessible, again, is the welfare stuff. Things that – I don’t think either service are particularly across – so, say food security. If your mental health is episodic and drug use is a part of that, you’re probably going to be broke, so off-pay week is going to be a problem. If you’re not eating properly, obviously your health, and therefore your mental health is unstable. There’s not enough access to the basic – the good old Maslow’s [hierarchy of needs]. So people worry about addressing a diagnosis or addressing a substance use problem rather than addressing living problems. [Currently] it’s all about reducing your needs, stabilising your mental health, medication, or just stop your drug use, and nothing in between. None of the basic human stuff that allows people to actually start making different decisions.”*

It is worth noting that some treatment models address welfare concerns better than others. For example, residential AOD services provide a focus for broader issues in residents’ lives. However, the comments above raise the notion that service users would benefit from more widespread holistic care.

This group speculated that part of the problem might be because there may not be a lot of networking between agencies. For example, one participant stated:

*“So, it’s a lot to ask of workers to be across all of the available services and in particular for any person who comes in there’s a whole variety of issues and they could be living wherever, you know. So it’s a lot to ask, but it’s also that kind of interagency networking amongst agencies isn’t really prioritised by or funded really, or time funded, for agencies themselves.”*

One participant raised an experience they’d had with how interagency networking might work:

*“I remember a couple of years ago I went to a consumer participation forum in Melbourne and one of the speakers talked on an interagency networking committee – they’d been established for 12 months, she [the speaker] said it’d taken the committee about 12 months for them to begin having a real conversation where the service representatives actually dropped their agendas and dropped their issues. One – it was amazing that the agencies provided the space and time for this to happen, but also two, it actually took time for that conversation to start to really happen.”*

This section raises the experiences of siloed services from a service user point of view. From the experiences disclosed, it can be gleaned that people with co-occurring issues might not view their issues as ‘co-occurring’ as such. Rather, they are viewed as part of the spectrum of symptoms people may experience when they are having problems in their lives. Siloing services appears to carry an expectation that people are required to compartmentalise their problems. However, focus group participants ultimately prefer to be viewed as those who are experiencing distress and doing their best to manage it.

### **3. How services and service delivery could be improved**

Each focus group was asked for their ‘wish list’ of what they would like to see happen to improve treatment in the sectors. This was explored by asking the following question:

- Based on your experiences, what suggestions would you make regarding service provision for people with co-occurring issues?

Again, themes were identified and will be discussed in turn.

#### **Broader conversations**

*“Yeah, there’s this misconception isn’t there? There’s a massive public misconception about drug use or mental health being a weakness and being an inability – lack of resilience and stuff like that.”*

It was widely agreed that more honest conversations at a broader, community level about pain, suffering and the collective human experience would help alleviate stigma and some of the fears people had when it came to admitting to an AOD and/or a mental health problem.

The need for more honesty in conversations generally was discussed across all of the focus groups. For example:

*“So that’s that broad community conversation where people actually are talking about how it really is for them in their lives and their struggles with the imposed societal structures and the boxes we need to tick to be acceptable and normal and part of – so I think more human conversation in general.”*

The notion of broader conversations extended to how people treat each other generally. It was raised that, perhaps, if people were nicer to each other, less people may develop significant mental health issues:

*“... if we did that more in the wider community: ‘G’day, how are you?’ – at the checkout chick or whatever, we said hello to them as a person and we treated them as a person – that in itself, if that was some sort of mental health – because that keeps people’s mental health and it helps keep people connected. As a preventative campaign I think that that should be out there...”*

The conversation further expanded to the preventative effect of teaching children how to identify when they’re not managing well, emotionally and mentally. This was viewed as being of particular benefit if stigma and other barriers around treatment seeking were broken down:

*“.. .if this stuff was taught in all schools, if kids were taught to recognise [that] ‘I’m thinking in this way, I know it’s not right, maybe there’s something going on in my body that’s not right that needs to be fixed’ rather than ‘I might go and see if Joe’s got a joint I can share with him’.”*

Another participant discussed the benefits of a shift in the language used to describe mental health.

*“... I would take away mental health – you know the Aboriginal – ECU did a website for Aboriginal health, Aboriginal Health Network. They’ve got their wellness section; they don’t talk about mental health. They actually don’t mention the words ‘mental health’, but they talk about all the things – about being connected, about wellbeing, relationships. So, instead of talking about mental health, talk about – wellness is a funny word, isn’t it – but wellbeing, like the ‘Wellbeing Commission’. Because what you speak is what you make happen and where does the stigma come from? It doesn’t come from the people that are unwell, it comes from all of these siloed things, you know. When you go into the mental health sphere, the reason people are so scared is because they know the way that it’s structured, you’ll never get out from it. They make you sick forever.”*

Another participant suggested that more education for the general public would help create more awareness for people:

*“... create awareness for people who want to know more about those issues. Maybe they should have more education for the general public...”*

'Broader conversations' became another area that was identified as potentially benefitting from peer involvement, by way of people with AOD and mental health issues histories sharing their experiences with a broader audience. For example, one of the participants raised that often people do not realise they have a problem because their presentation does not fit stereotypical conceptualisations, and if people who identified as having issues were more visible, the wider community may become more aware of the heterogeneity of people with AOD problems:

*“And then, as far as education to the wider public, getting lived-experience stories out there that aren't this person in a box – I mean, so many people come in to [name supplied] and it's like 'I'm not an alcoholic because I'm not with a brown paper bag in a park'. Me actually sharing that I am an alcoholic [I get] 'You? You're not an alcoholic, you don't look like one'. So getting people's stories out, whether it be social media, advertising, whatever, just so you can help destigmatise and take away those rules we've got in our heads about what a drug addict looks like...”*

Another participant further noted that they felt they had a role to play in normalising conversations by sharing their experiences:

*“I think you raised a good point about the normalisation of the conversation around that. I personally think that I have a part to play in that because it's so much easier to say I was diagnosed with a mental health problem then it is to say I'm an addict. That I used drugs, that I put needles into my arm – to say that kind of stuff, to say 'this got so crazy that I went to this'. Because people, you know – and even within the drug use – like, how far you go, it's a little bit worse – so to me it's people with lived-experience getting out and sharing our stories as community members.”*

Conversations that break down stigmatising barriers can have the effect of, not only changing the way people see those with AOD and/or mental health issues, but also changing the way they treat them. As one of the participants pointed out:

*“People must be treated with dignity.”*

### **Expanding the peer workforce**

***“For me, I think we need to engage more lived-experience peer workers apart from the professional clinicians...”***

All focus groups discussed expanding the role of the peer workforce and examined how this could occur within the AOD and mental health sectors. The discussions included several suggestions. A couple of the focus groups discussed the role peers could play in helping new clients feel comfortable in a service. For example, a number of participants discussed the benefits of having peer workers to greet new clients, in order to help alleviate some of the anxiety often felt by people who had not sought treatment in the past:

*“... in regards to the peer workforce and having more access to that, particularly – it might facilitate people's engagement of services, because if you've got peers in front of house – it's quite an intimidating thing to come into a service for the first time so if*



*someone's actually made that step and come in, whether it's friends, family, the person themselves, or whatever – if you've got peers in that space to do that warm engagement you're going to create that safe space for them and normalise that experience, and help that pathway stuff...*

And:

*"... increasing your peer workforce to do that warm facilitation to your engagement. They're going to facilitate your engagement. They're valuable to a service. If they want outcomes, get your peer workforce to facilitate that engagement and they'll improve your outcomes."*

And:

*"But this is the value of your peer workforce. Often your admin don't have the capacity – they're flat out doing paperwork, this that and the other, managing staff, managing front desk, managing – they don't have the capacity of being nice to you, there and then..."*

The perceived merit in this suggestion was encapsulated in the following quote:

*"... there's a big desk, there's a person behind the desk and it's kind of like there's a barrier and there's this power imbalance. I felt like a small kind of animal, crawling in – going into a room, hidden away. That's hard on my mental wellbeing."*

One of the participants discussed some of the potential issues with the peer workforce for services, but maintained the fundamental importance of the level of understanding that those with a lived-experience can offer:

*"... and I guess I understand agencies' hesitation around the peer workforce because how do you regulate them, how do you know that they're quality peers and are going to say the right things and give the right advice and what if they give advice and it's wrong and they kill themselves and like, all this blah, blah, blah. It's an area of concern obviously, for an organisation and their accreditation, but it's addressing that human need and that need for connection and understanding, you know."*

Most of the focus groups felt that a stronger peer workforce would be able to provide advocacy and mentorship for people who are too unwell, or for other reasons, to ask for help. A couple of participants articulated this point:

*"... when a person is unwell, they can't take responsibility for themselves. I mean, yes, you have choices and things, but ultimately you're so unwell that you can't really take full responsibility for yourself and knowing what questions to ask."*

Ways in which this could be integrated into services was discussed. Participants in a couple of the focus groups noted that there are services that people need to engage with, whether they want to or not. These services could provide an opportunity for peer workers to engage with vulnerable people who are unable to access treatment services. For example, one of the participants suggested:

*“And what about advocacy in those places that you go? So you go in... and why is there not someone with lived-experience? They’re not in the – in those service providers... [facilitator: talking about law, corrective services, Centrelink?]?... Yeah... why are we as people with lived-experience not in those places? We’re all saying that we need someone to say ‘me too’ and all that, but in all these service providers...”*

And:

*“The systems need to be – like AOD, mental health, welfare, all of that – needs to be able to catch us as individuals in those places where we don’t have the skills...”*

And:

*“... what you just said about Eds [emergency departments]. Getting peer workers into – I can see some barriers to that, but maybe like, because I certainly wound up in ED all the time, but to have somewhere to go for – even if it’s the day after that – some sort of clinic where you can go and then have the peers come in... even if it’s not detox, but somewhere you can go that’s safe for a day and then have peer workers come in and say, ‘look, I was in your space two years ago, this is what helped me’. Once their head is a little bit cleared but before they go out the door.”*

One of the focus groups discussed the idea of peer workers providing a more active response for people when they exit treatment. This response would include peer workers actively contacting people when they leave a service. For example, one participant shared:

*“When I was in [name supplied] there were all these guys being discharged. Now I knew, I was pretty much almost positive that three of them that were discharged had nowhere to go... What follow up is there for them? I would dearly love to see... you didn’t get discharged into their care so to speak, but if somebody rang up to say ‘How’re you doing?’ after three or four days or every other day after the first couple of weeks and then gradually tailed off...”*

Participants felt that this would allow for people to maintain connections, and provide the offer of support to those who, for whatever reasons, are less likely to proactively seek aftercare. As the quote below identifies, people often do not get the tools to manage their issues until they’ve been in recovery for long enough to learn some:

*“... well, I’ll speak from my own experience – you’re changing hats all the time, you’re – I didn’t have any sense of my personal boundaries nor any self-awareness that I was actually slipping. It’s not until you’ve got a few tools and you’re a little bit more into your recovery that you can use your – those tools to know when you’re not travelling well. And set those boundaries. Otherwise you end up burnt out.”*

## **Service aspects**

***“So, whether they had more group programs or teaching more life skills would be ideal.”***

All of the focus groups identified aspects of service delivery that they felt could improve in order to enhance treatment outcomes. For example, there was discussion around enhancing the variety of treatment options that are available to people. One of the recommendations put forth was having a greater range of treatment options that met the wide range of needs that people with co-occurring AOD and mental health issues may have.

Currently in WA, treatment in the AOD sector predominately consists of weekly counselling, therapeutic and support groups (either formal or informal), withdrawal services and residential rehabilitation. A number of the participants identified what they saw as a gap in service delivery was a short-term rehabilitation to fill a gap between withdrawal and long-term rehabilitation, for those who were unable to commit to a longer treatment approach, but would benefit from more intensive treatment than weekly counselling:

*“... there’s just not detoxes that are short term, there’s no 30-day rehab in... it’s a long-term commitment. It’s not easy for people with lives and stuff and other commitments. Even a 10-day thing. Just easy detox, reset and a bit of help. It’s just not available.”*

And:

*“So like a dayhab. Even for workers, you could go to a Saturday morning-hab. I don’t know. Saturday night – something.”*

There were similar suggestions regarding appointments in the mental health sector. One participant spoke of more treatment availability in this sector:

*“I think there needs to be... longer term treatment... I needed more than just a one-hour session once every month or so. So, whether they had more group programs or teaching more life skills would be ideal.”*

Following on from the conversations across all focus groups on the issues with waitlists, discussion highlighted that if there were more treatment services with less entry criteria, more people would get immediate access:

*“Address your immediate access, address your detox – i.e. more of them and less restrictions to help you do that as safely as possible.”*

One of the participants suggested that a way of making treatments more accessible to people could be to get the private and public sectors to work in better concert with each other:

*“... to have some marry up between public and private because at this point in time ... you are either one or the other, you cannot – nothing is integrated, you can’t – if you access one, you can’t access the other and it’s just absurd that it has to be like that. You can’t try and tailor any treatments to a person’s actual needs because you can’t access who might be the most appropriate person or service from either part of the sector, public or private. At the moment there is just this utter divide... there’s no – you can’t put yourself on a public list if you’re registered on a private psychiatrist [list]. It’s just utterly absurd at the moment.”*

Another participant suggested a central hub for people to receive support and advice. This idea would also address another issue that was raised – that people were often unaware of what treatments were available:

*“I think as far as not only information but accessibility through that information, you know, a central hub. Ideally online would be a great way to start. Call it ‘Recovery Hub, call it ‘Wellness Centre’ – whatever you want to call it, just somewhere someone can go. Even if they don’t know what their problem is, even if life is just rough for them and, you know, maybe answer some simple questions... it’s like, you know, a button to click on where, if your life is in the pooper, and then it funnels you through some very unobtrusive, simple questions and then goes, ‘ok, maybe residential is not good for you so I’ll put you on this pathway’.”*

There were some issues identified with technological aspects of this suggestion however. For example, one of the participants discussed the possibility that some people may struggle with navigating the internet:

*“I think it’s a big resource for young people and maybe people take it as a given that everyone can access that service as easily as functional people...”*

And:

*“There’s definitely a gap isn’t there? And then with the drugs and mental health there’s often – you’re either self-medicating, you’re possessing drugs so you’re risking going to prison or something or you might be doing something – another way of funding it and they go to prison and they fall through the gap. I ran into a guy outside here last night who’s been in and out of prison and he’s not even that old, he’s 36 or something like that. [He has] no idea how to use technology and stuff like that really and he’s like, ‘man, I don’t feel like I fit into this world’”.*

Some of the focus groups explored the notion of having centres where staff could be employed to provide advocacy for people who need it. For example, one of the participants shared the following experience:

*“And my other biggest thing is advocacy centres, because if you’re on a waitlist and you’re not able to get help from an organisation in particular you could have issues coming up like [name supplied] are going to kick you out or things are going on and you’re going to go to jail for something. If there were advocacy centres around the place where people with mental health and AOD issues can just go and say ‘this is what’s happening, I don’t know what you know’, because I’ve had experiences where I’ve rung [name supplied] myself, given them the blurb because they hadn’t charged me rent or something and they wanted me to back pay them, given them the whole blurb and then had my [name supplied] worker arrive at my place while I’m in tears because they wouldn’t listen to me and [had the worker] call them up and tell them the exact same words that I had told them and got a result. ‘Oh tell her not to worry about it, we’re not going to der-der-der-der-der’. I was gobsmacked, because I sat and listened [to the worker] and [thought] that’s exactly what I said to them!”*

The concept of 'no wrong door' was raised:

*"... we need to make sure than when the person is ready, when they get to their own individual breaking point there is no wrong door for them to walk through to get the help they need and that the help is empowerment of the self and your own recovery"*

It was suggested that this could be in the form of a 'safe place':

*"But the concept of safe space, somewhere people can go because they can't take care of themselves, that they can be taken care of and treated humanely in a nice looking place."*

One of the participants noted that sometimes people with AOD and mental health issues lead chaotic lives and it can be difficult to make and keep appointments. It was suggested that a place where people could 'drop-in' for medical support would allow people, who are not currently managing, to access support as they need it:

*"... to have a one-stop shop type of thing where you don't need to make an appointment to come in and see a nurse, just come in, and all that sort of thing, I think helps. And especially for people with AOD and mental health issues, our lives can be quite chaotic at times and, you know, especially with peers, I think it's a huge help."*

There was a sense that there was a perception across the sectors that a 'one-size-fits-all' approach to working with clients was sufficient. A number of participants stated that they would like to see this perception shift. For example:

*"Well isn't that what we've all said here today? What we wanted was people to actually listen to us and to meet us where we're at, not have some pre-idea where we should be. This is the problem with the sector as well – we've got these well-meaning people, and I'm over generalising here, from the western suburbs who wouldn't know what it's like to talk to somebody who's been living in Balga, because it's a whole different language."*

Importantly, one participant noted the need for services across both sectors ensuring all aspects of service delivery are trauma-informed. This participant articulated this in the context of how a service's environment can perpetuate power imbalances:

*"Trauma informed work, [that's] number one. [Facilitator: So everywhere becomes far more trauma informed?] Yeah and just like, the environment is trauma informed as well. Even coming into a big building like this, for me, is kind of like - it's not easy. It's daunting because it's not something that I'm used to..."*

This comment further highlights the importance of services paying attention to their environments – are they safe? Are they welcoming? Will consumers feel comfortable in this space?

Participants across the focus groups felt that services needed to widen their expectations of treatment focus. For example, it was felt that many services expected their clients should have abstinence as their AOD-related goal, and this was unrealistic for many people:

*“... I don’t think services’ focus should be on abstinence. ‘Right you’re all going to be sorted from here on in.’ Because it’s progression, right, it’s like some safety, give the person some skills or ideas around what they can do if shit goes down or some services available to help. Just get them safe, get them level, then give them a bit of information for them to consider and then when they go back out there, things might be, you know – it’s not about saving someone right here, now and forever. It’s about giving them the skills and contact with services that are going to help them in the future.”*

Another participant raised that people may be more likely to attend services, even if they are still using, if they knew they were going to be heard and not judged:

*“Yeah. Someone to be there on the journey with you, I guess. And where information is more readily available. And making it more easier to talk about your problems, like wanting to go and get help, even mid-use. Having the knowledge and where to go and not like, [the worker] sitting there and shuddering and thinking ‘I’m going to catch something off you’. Making it ok to talk and ask for help.”*

A couple of the focus groups discussed the need for better aftercare for when people exited a service. For example:

*“... my experience was getting housed in – you know, I could only afford a single room in a house and each place I was housed for the first three years after coming out of the mental health unit were very avid drug users or dealers that I was sharing a house with and it wasn’t a positive.”*

And:

*“I guess from another negative experience my wish list for both sectors would be better safe housing opportunities after – yeah.”*

One of the participants discussed broader strategy that would benefit people with in need of housing support:

*“Look houses are cheap now because the market is really low – buy up houses. What’s [name supplied] doing? They’re selling houses – you should be buying up houses because people don’t want to be in wards. They want to be in a house.”*

There was agreement across all focus groups that greater awareness of what services are available and how to access them would be an important future direction for people struggling with issues. This is articulated in the following quote:

*“I think this is a really important question and you can assist a lot of people [to become] aware of what’s available for when they do run into trouble. You’re not going to stop people from running into trouble with this, it’s part of our collective human*

*experience. Drug use is going to be there, but if people are aware of the avenues for assistance when they need it, it's just going to make things maybe a lot easier."*

Lastly, a couple of the focus groups discussed the way they perceive organisations spending their funding. Participants in both noted that it sometimes appeared that money was being spent on things that they deemed unimportant, at the expense of treatment:

*"One of the things that I'm very – feel very strongly about, and I don't know what can be done about it, is – a lot of emphasis in all of the departments and organisations, etc. – it's always going to be about how can we save funds and get the best possible outcomes on the minimal amount of money. My pet hate is that within this – or I've noticed it within these two realms, AOD and mental health – that a lot of money is often spent on changing names, logos, all that stuff, which means absolutely nothing to us. I don't care if you're called [name supplied] or if you're called Dog Shit. I really don't care. That doesn't matter to me. But when a whole lot of money is spent on that when there are people around [who are] suffering [and are] unable to get any help or support because of waitlists are this long and all that sort of thing – put that money into an extra venue with extra beds. I'm just over it and it's happening all the time."*

However, it was noted by a participant who works as a peer in a service that often the way funding is structured can get in the way of service delivery:

*"And you know, like at work – we get frustrated because it's not under our genre that we're funded to do and we kind of get told off a little bit if we do it because that's not what we're funded to do. And then it's like if you do it for one you've got to do it for everybody and we're not funded to do that. It just makes it a big mess. So you know – it's that horrible word, funding".*

### **Worker aspects**

Given the weight all of the focus groups put on their relationship with their workers as being a significant contributor to their recovery, it is unsurprising that aspects of the client/worker relationship that could be improved were discussed in this section. Whilst it was acknowledged by all focus groups that the value of a strong relationship with workers cannot be overstated, it was felt that there were some aspects of the relationship that workers need to be mindful of.

One of the participants, who had engaged with various services for much of their adult life, spoke of feeling uncared for. They would like workers to care more:

*"What they can do better is 'give a shit'".*

Much of the discussion around worker aspects centred on the balance of power in the relationship between client and worker. For example, one of the participants felt that it was currently difficult for service users to voice when they did not 'fit' with a worker. They felt that making this process less consequential would be beneficial:

*"Less consequences if you're upfront about not fitting with a worker."*

Another related aspect is the notion of partnership in treatment, as one of the participants alluded to:

*“Doing it with people, not to them.”*

A couple of participants raised that they found it beneficial when they felt in control of their treatment and would like to see more of this:

*“And allowing them to stay in charge. Stay in control.”*

One even shared the type of treatment that can guide this:

*“Use of life maps to help drive treatment focus – allowing people to identify their own needs.”*

It was noted by some of the participants that, if a worker wasn't engaging with their client in a way that was meaningful to the client, it may have more to do with the nature of the job and structural issues that are out of individual workers' control than the worker 'not caring'. For example, one of the participants articulated:

*“People just get stressed out, the workload is just too much and that's where it starts to come across as people don't care – it's because they've just got such a heavy workload...”*

### ***Integrating the AOD and mental health sectors***

***“... instead of the AOD sector being over there and the mental health sector being over there, why can't we integrate them all in together?”***

There was bemusement amongst the participants around AOD and mental health being separate sectors. Given there was consensus that it didn't *feel* separate in individuals, there was very little understanding of why this is the case in service provision. There was common agreement that mental health workers and AOD workers should be in the same service. There was also common agreement that it would be ideal if workers were skilled in both AOD and mental health, meaning they would have their needs met by one worker, rather than have a range of services in their lives. For example:

*“I think each organisation should have skilled professionals from both fields so that when a client is engaged and maybe they're engaged with a mental health worker, let's say, and they establish that they have AOD issues, they can be dually treated. I was just fortunate enough to have someone who had both skills...”*

This series of focus groups has highlighted that when workers honour the client's change agenda, change is made. Indeed, conversely, when workers attempt to drive the agenda (often driven by organisational policy) that clients can feel uncared for and are more likely to disengage.

A shift in language was considered as perhaps a way to integrate people's thinking about AOD and mental health. For example:



*“I actually think we need to break down the lines of why there is an AOD and mental health sector. Why are AOD issues not actually acknowledged as a mental health – like the language around it.”*

One of the focus groups discussed the idea that if workers in agencies were afforded the time, and encouraged to network with workers from other services across the breadth of sectors, there would be better interagency collaboration:

*“It’s just that prioritising of that interagency knowledge amongst workers in services and those interagency relationships, like managers giving their staff time and prioritising that kind of get together for that to happen.”*

One of the focus groups discussed an expansion of the Alcohol and Drug Support Line (ADSL) to include the mental health sector. ADSL is a 24 hour, 7 day a week, telephone counselling, information, support and referral service for people who are impacted by their own or someone else’s AOD use. It also serves as a single point of entry into the AOD sector in WA. Whilst it is acknowledged that the mental health sector does have a number of telephone advice lines in WA and nationally, this was not raised by the participants. There was acknowledgement that the mental health sector does have a number of telephone *crisis* lines. According to one participant: *“the perception is they are there for people that are in a crisis”* However, the distinction was made that ADSL was not a crisis line as such – consumers can telephone if in crisis, or for counselling and support, or service information. From participants in this focus group at least, it appears that telephone lines in the mental health sector are not viewed in the same way as ADSL. It was reasoned that not having a central number to call for mental health-related concerns makes it difficult for people to navigate the mental health system. This reasoning led to discussion about what a mental health line might look like:

*“You’ve got that intermediary non-crisis phone line to connect to somebody in the alcohol and drug space. That’s missing in the mental health - could there be a convergence of like, a chat line...”*

It was suggested that this service (ADSL) could become a line for mental health consumers as well. Another participant described a ‘warm line’, which was a telephone line that was not a crisis line or a counselling line – something in between: “...

*“...is someplace where you ring up and the person taking the call is trained to listen and that’s all. Not to offer advice, just to listen”.*

Furthermore, it was reasoned that having the availability of this type of service in the mental health domain would fill gaps in service delivery for clients and, potentially, lessen the strain on services. ADSL provides counselling, information, support and referral to the community of WA concerned about AOD issues. ADSL also provides services system navigation and treatment matching to better support the consumer getting to the help they need as close to home as possible (S. Child, Manager Alcohol and Drug Support Services, personal communication, September 11, 2020). Given the complexity of the mental health system, it is

reasonable to consider that this type of service would be beneficial for mental health consumers.

A number of participants raised that they felt staff in both sectors would benefit from more integrated training, and that this would ultimately benefit consumers with co-occurring AOD and mental health issues. For example, one participant noted that, in their experience, a lot of mental health workers did not have competency to work with people who use AODs:

*“... many of the clinicians of allied health in the public hospital sector, they are very well competent in the mental health, but I find in the AOD they are not competent enough to tackle those issues.”*

It was further suggested that medical staff have access to more training:

*“Maybe they should kind of shift more training in that area. Even the young, or the new nurses or the doctors or the whatever...”*

Another participant noted training around a more integrated approach would be beneficial:

*“Better training, integrating mental health and AOD in a much more better way, much more holistic approach and better training, and lobbying to get the money to do it...”*

One of the focus groups felt AOD and mental health services would serve those with co-occurring issues better if they co-located:

*“So instead of you having one at Fremantle and another at Joondalup, why can't we have them meet in the middle?”*

As one of the participants pointed out, it is often difficult for people to access services:

*“I'm finding, through facilitating support groups and running information sessions at the hospital, that people can't get to support groups. They do not have the money for bus fares, for petrol and sometimes their mental health is so bad they can't even get out their front door.”*

If service integration is not feasible, co-location of services may ease a lot of the issues consumers can have around simply managing to physically access services.

# Discussion

This series of focus groups, attended by people with a self-identified lived-experience of AOD and mental health issues, gave good insight into the facilitators and barriers to treatment access, what works and what doesn't, and perceived areas for improvement. Whilst the perspectives raised can only be representative of those who raised them, the issues discussed are likely to be pertinent to others with co-occurring AOD and mental health issues who may or may not access treatment services. Indeed, many of the issues raised in this series had previously been discussed in the 2016 focus group, suggesting that many of the issues facing the people in these focus groups are likely to be faced by many others with co-occurring AOD and mental health issues.

The first set of questions addressed barriers to treatment seeking. The themes explored highlight the many and varied reasons people with co-occurring AOD and mental health issues can often spend a lengthy period of time in significant distress before accessing help. In particular, stigma, the fear of consequences and not identifying issues as problems that can be alleviated through treatment were significant barriers to treatment-seeking.

Stigma was cited as one of the main reasons people did not access treatment, particularly when it has been internalised. People felt less deserving of treatment and less able to manage the judgement of others. This impacted the way the participants viewed themselves and many stated they felt it necessary to keep their symptoms hidden. This, in turn, meant that they were more likely to only access treatment when their symptoms became so severe that they were unable to hide them. Often, then, they felt that they were forced into treatment in a way that was mandated and felt punitive, i.e. through the justice system or child protection. All of the focus groups spoke of the need for society in general to start having more honest conversations about human suffering in order to break down stigma and the fear and shame it causes.

Another negative aspect of the shame and secrecy that stigmatising attitudes cause that arose from these focus groups is that people do not get to learn from others what having problems looks like, nor do they learn from others how to manage their symptoms when they are acutely unwell. This aspect is closely related to another significant factor that delayed treatment seeking, which is, not recognising that their problems were symptoms of issues that could be treated, particularly for mental health issues. Most who'd disclosed that this had been a concern for them stated that this was because their concept of what 'mental illness' looks like tended to be when someone appears stereotypically 'mad'. It is theorised that, if people did not feel the need for secrecy and experience the associated feelings of shame, they may be generally more open about their issues and this would in turn help others identify when they are having difficulties that could be treated.

Many of the participants disclosed that they were simply unaware of the types of treatment and services available. Interestingly, similar comments were made by consumers in the 2016 focus group (MHC, 2016). To further complicate this, many of the participants stated that they also delayed seeking treatment because they were fearful of the consequences.

This was regardless of whether their primary concern was their AOD use or their mental health, albeit for different reasons. For example, participants stated they were fearful of drawing attention to themselves if they disclosed drug use or risked being forced to make changes to their drug using behaviour that they did not feel ready for if they sought treatment for their AOD use. In contrast, some of the participants stated they were fearful of being placed in a locked ward if they disclosed mental health issues. Both findings suggest that there are some problems in communication from both sectors about not only what is available, treatment-wise, but also what treatment entails. Both sectors may benefit from broad, community-based discussions aimed at providing a better understanding of what treatment actually entails.

The barriers to treatment that the participants raised are particularly pertinent when considered in the context of the amount of support many of the participants felt they needed in the early stages of their recovery. A number of participants raised that, in retrospect, they felt they'd needed a high level of support at this time, but they were unable to identify that they needed support. Furthermore, they did not have the assertiveness to ask for the type of support they needed. This commentary suggests that there are significant barriers to treatment seeking that occur when people are least able to manage overcoming barriers.

The second section was concerned with the aspects of treatment that facilitated or hindered recovery, and the roles that services played in this.

Most of the participants in this series of focus groups communicated that they felt that having access to a peer network for support was considered a significant facilitator of positive treatment outcomes. There was overwhelming agreement that the availability of peer support within services helped consumers to reduce the anxiety of engaging in a service for the first time, particularly within the context of the inherent power imbalance between the service and the consumer. Furthermore, having peers present and visible in a service communicated to service users that they would not be judged and that they would be understood. Again, this concurs with the commentary on peer support in the previous focus group (MHC, 2016); lending weight to the notion that, for many, peer support is a welcome aspect of service delivery.

Autonomy and choice were noted as important considerations for, not only the types of services to attend, but the type of treatment once engaged in a service. This theme was largely concerned with the service user being the one whose change agenda was the one worked towards. There was a feeling amongst the participants that this was not always the case, and that their wishes were not always heard by the people treating them. Most participants maintained that their outcomes improved when they felt they were able to set the agenda for their own treatment.

A number of service aspects that hindered treatment were discussed. The presence of waitlists was often cited as having a significant negative impact on change momentum. There was acknowledgement that it is a difficult issue to fix for individual services (as one participant stated: "*Mind you, what can you do about waitlists?*"). However, it is worth noting that the experiences of the focus group participants regarding being waitlisted and change

momentum is consistent with broader commentary on the subject (e.g. Ritter, Chalmers, & Sunderland, 2013).

Consumers' relationships with their individual workers was another factor that either aided or hindered the recovery process. Indeed, it should be heartening for workers to know that they do make a difference. This is consistent with research around the impact of this relationship on client outcomes (Miller & Moyers, 2015). Aspects of the client/worker relationship that were viewed as beneficial included the sense of being cared for and listened to, as well as workers being seen to take the time to conduct home visits. Relational aspects include a strong therapeutic relationship and the worker's ability to convey empathy (Miller & Moyers, 2015) which largely concur with the participants' descriptions of worker characteristics that were helpful.

Staff turnover was another issue that was seen to interfere with recovery efforts. This was generally because the participants found it tiresome to have to repeatedly tell their story. There is no simple solution to staff leaving their positions, however the impact this can have on people accessing services should be acknowledged. Service users may begin to feel discouraged about developing a relationship with workers because they may have developed mistrust that workers will be around to see them through their treatment. To counter this, services can support 'warm' handovers. This involves the outgoing worker facilitating a smooth transition for the client to the new worker by bringing them together and ensuring the continuation of the client's therapeutic process (Gavazzi & Anderson, 1987). Research suggests following this process can go a long way towards alleviating client frustrations about having to retell their story (Clark, Robertson, Keen, & Cole, 2011).

The discussion around which service and worker aspects helped or hindered recovery mainly concerned the service's structure and policies that did or did not facilitate engagement and, thus, treatment outcomes. This included service users having the right to voice their dissatisfaction with a particular worker without fear of negative outcomes. Many services would have provision for this in their policies, however, the inherent power imbalance between service and service user may account for the service user not feeling able to speak up on this issue. Ways of making this process more explicit and accessible should be explored.

Other service aspects that participants noted can influence the therapeutic alliance included consumers' perceptions that some policies are punitive and that service requirements can be too rigid. If service users perceive that the service is more concerned with policy over people, or funding body requirements than meeting their treatment needs, they may not enter into a therapeutic alliance with their individual worker. Some policies were seen as particularly punitive, for example, a couple of participants described being denied access to pain medication because of their drug use history, despite being in considerable pain at the time. Furthermore, it was felt that agency reporting and funding requirements sometimes held priority over client outcomes.

All of the focus groups discussed siloed services as being an aspect of how the way service is structured hindered recovery. It was further noted that conversations about siloing should

not be limited to AOD and mental health services. People with co-occurring AOD and mental health issues often have a range of other service needs and it was suggested that these should also be considered in any conversation about de-siloing. This suggestion has merit and is often overlooked when the notion of siloed services is discussed. Currently, services tend to not coordinate care; it's largely up to the individual to navigate systems. This report has already discussed some of the issues with this – namely that people are often unaware of what is available and do not often have the internal and external resources necessary to manage multiple systems. This means that people often do not get their needs met and end up 'falling through the cracks'. Marel and colleagues (2016) highlight the increased recognition of the need for services and sectors to take a more holistic approach to client care, enabling clients to have the broad range of their needs met, such as physical health, housing, justice, family issues and employment. They recommend coordinated care, whereby workers (often designated case workers) support their clients in referral and discharge practices to access support for all of their identified needs. This requires that services develop and maintain good relationships and referral practices with each other.

The third section asked participants what the sectors could do to improve service delivery. Normalising human struggle as a way to breakdown stigma was discussed across the focus groups. It was largely felt that the broad, social tendency to minimise mental or emotional difficulty created a culture that tended to deny their existence. This can impact broader perceptions of people who use AOD in particular because others are not privy to their motivations around their AOD use. This issue was raised at a 2014 forum held by the Western Australian Association for Mental Health (WAAMH) and the Western Australian Network of Alcohol and Other Drug Agencies (WANADA) that invited consumers and their carers, as well as representatives from both sectors, to discuss service improvement. Community attitudes towards people with AOD and/or mental health issues was raised in this forum also, and suggestions of a community education approach were given in order to combat the stigma that is associated with these issues, suggesting broad support for the idea (Western Australian Network of Alcohol and Drug Agencies, 2014).

Expanding the peer workforce was an unsurprising suggestion given that most people across all of the focus groups spoke of the advantages of peer contact. Again, this concurs with the comments made by participants in the 2016 focus group (MHC, 2016). Expanding the availability beyond the AOD and mental health sectors could be widely advantageous for the more vulnerable consumers. It was pointed out across the focus groups that people who are vulnerable are often unaware of their own vulnerability and struggle to recognise that they need support. It was felt that the types of services that require attendance, such as Centrelink, would be well placed to provide some kind of peer support, with an aim to bridge this gap. It was, however, noted that there needs to be structures in place that do not disadvantage peers or service users. For example, a clear understanding of what a peer is and is not needs to be held by the service and communicated clearly to all consumers wishing to become peers. Furthermore, peer support workers need to be adequately vetted and supported by services (O'Hagan, 2011).

Most participants discussed expanding the types of treatments that are available, theorising that more variety will suit a larger number of people. It is worth noting that a number of the services and treatments they suggested either do or have existed. However, given that lack of awareness of what treatments are available has been cited as a barrier to treatment, this is perhaps not surprising. It is further worth noting that the focus groups consisted of consumers who have already navigated the service systems and were still unaware of a lot of what is available. This suggests there may be problems with the way the sectors promote themselves. It is possible that people are generally unaware of the types of services that are available until they need them. However, it was often pointed out across all focus groups that people who are unwell might struggle to find the services they need when they need them. Therefore, there may be merit in considering the ways in which both sectors promote their services to ensure that what is available is more known.

Most participants discussed integrating the AOD and mental health sectors. This approach is seen as a way to break down the siloing of the two sectors.

# Conclusion and future directions

This series of focus groups raised salient points about what is and is not useful in treatment. Whilst it would have been ideal to get a better sense of what the individual sectors were doing well and not-so-well, given that none of the participants viewed their issues as separate from the other, it makes sense that they would not distinguish between AOD and mental health services. However, what was apparent was that the consumers generally wanted services to take a whole-person view and help them examine all of their problems – not just their AOD and/or mental health issues. They wanted to feel as if the people working with them cared about what happened to them. ‘Person-centred care’ has been conceptualised by Marchand and colleagues (2019) as consisting of four principles:

- Integration of a holistic approach that takes into account the client’s bio-psycho-social influences
- Individualised focus on the client’s unique needs, preferences and goals
- Shared power and responsibility between the client and healthcare provider
- Development of a sound therapeutic alliance

This conceptualisation largely mirrors the treatment experiences that facilitated positive outcomes for the participants in this series of focus groups, suggesting the utility of this approach.

Of further consideration is the utility of focus groups. There needs to be a commitment from people who conduct focus groups with consumers to ensure something of value comes from them. As one of the participants (very reasonably) stated:

*“Better training, integrating mental health and AOD in a much more better way, much more holistic approach and better training, and lobbying to get the money to do it, and not just yabba yabba and have workshops and that and what happens after the workshop? Where does it go, what do you do with it? Where’s this going to go – we need to know what the results are going to be. I’m not here for the money; I’m here to make a difference. I’ve done so many of these, I can’t count them. I want to know, you know, what’s going to happen? What’s the conclusion – you’ll give us the report to look at, ok we’ve ticked the box to look at it – I’d like to know the conclusion of it when it’s submitted. There’s another step to be taken after this.”*

This series of focus groups were designed for and used to enhance the content of the Keyworker Plus training package. However, the insights gleaned are worthy of use beyond this. Given the reach of WFD’s training generally, the content will be used to illustrate concepts more broadly. It will also be used to educate workers in the AOD, mental health and allied fields of the experiences of people who access services. Embedding the consumer voice in all trainings will ensure the ‘voice’ reaches the people who are best placed to support treatment outcomes. In this way, the needs and frustrations of consumers can be communicated to workers at an individual level.



The final word should belong to one of the consumers. They are asking those of us who work with them to continue to push and dream and consider new ways of doing things:

*“Don’t spend big. Dream big. At the moment there is – I don’t really see a future for all the people that we’re trying to address the needs or circumstance of, but I think it’s not a question of spending, it’s a question of just – of vision, of going beyond the bounds that people have set for how you do this now.”*

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## Appendix A: Consent to Participate Form



Government of **Western Australia**  
**Mental Health Commission**

### **Consent to Participate in Keyworker Plus Focus Group**

Thank you for agreeing to participate in a focus group run by Workforce Development (WFD) at the Mental Health Commission (MHC).

#### **The Purpose of the Focus Group**

This focus group is part of the Keyworker Plus project. This project, funded by the WA Primary Health Alliance (WAPHA), aims to improve service delivery to consumers with co-occurring mental health and alcohol and other drug (AOD) issues by upskilling staff in both sectors in working with people who experience co-occurring issues.

The purpose of the focus group is to:

- gain a better understanding of the experiences of individuals who experience mental health and AOD issues whether or not they have engaged in services in both sectors
- understand barriers to seeking services and support
- obtain insight into what services are currently doing well and how they could be improved

After the focus group we will write a report on the findings of the focus groups..

#### **Participation**

Your participation is completely voluntary and you may withdraw from the focus group at any time. The focus group will take 1 ½ - 2 hours. You will be paid for 3 hours of your time.

#### **Confidentiality**

You will be attending the focus group session as part of a group, meaning other participants of the focus group will be aware of your participation. The MHC requests that you do not share any information about other participants of the focus group without their consent.

All information from the focus group used to inform the MHC's work in the future will be de-identified. This means that we will not use your name, other identifying information or other personal details without your written consent. **This consent form does not include consent for us to use identifying information.**

This focus group will be recorded to allow WFD to make sure all information participants provide is captured correctly, and to provide WFD an opportunity to reflect on the information collected. Following the focus group, the recording will be transcribed. The recording and transcription will be securely stored at the MHC. The information collected will be kept strictly confidential. No identifying information about you as an individual will be collected or stored.

A written report of the information gathered from the focus group will be produced by WFD, which will be made available for download from the MHC website (subject to approvals). No identifying information will be written in the report. Please tick the box below if you wish to review the report before it is published.

The recording will be disposed of once it has been transcribed. The transcription will be kept securely in the MHC record keeping system as per the State Records Act 2000.

**Risks**

Your participation in this focus group requires that you volunteer or share personal experiences and information, with no anticipated risks associated with participating. Every effort will be taken by WFD to ensure you do not feel discomfort by participating in the focus group. You will not be required to respond to any question or share anything that you do not wish to.

Please see the attached Focus Group Questions document to have a look at the questions which will be asked during the focus group.

If you have any further questions about the focus groups please speak to the facilitators at your focus group session.

**Withdrawal of consent**

You can withdraw your consent to participate in the focus group at any time. Once the focus group is finished, because we will not know who is speaking on the recording, it will not be possible to withdraw your consent to use the information from the recording.

**Acceptance**

Your signature on this form indicates that you:

- 1) understand the information provided to you about your participation in this focus group, and
- 2) agree to participate in the focus group.

**Participant's Name** (please print): \_\_\_\_\_

**Participant's Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**MHC Staff Name** (please print): \_\_\_\_\_

**MHC Staff's Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

Please indicate if you would like to review the report prior to publication

**Your email:** \_\_\_\_\_

## Appendix B: Focus Group Questions

### Focus group questions

1. If you haven't engaged in either sector, why not?
2. If you have only engaged in one sector, why?
3. As a person with a lived experience of AOD and mental health issues, tell us about your experience of being a client in mental health specific services?
  - a). What were the things (people, types of service e.g. counselling etc.) that helped? Why?
  - b). What were the things (people, types of service e.g. counselling etc.) that didn't help? Why?
    - Barriers (e.g. waitlists)
    - Access (e.g. availability of services)
    - Comfort with disclosing 'non-presenting'/other issue
    - How well did each service manage the 'non-presenting' issue
4. As a person with a lived experience of AOD and mental health issues, tell us about your experience of being a client in the AOD specific services?
  - a). What were the things (people, types of service e.g. counselling etc.) that helped? Why?
  - b). What were the things (people, types of service e.g. counselling etc.) that didn't help? Why?
5. Based on your experiences, what suggestions would you make regarding service provision for people with co-occurring issues?





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