



VICTORIAN SERVICE USERS' EXPERIENCES AND NEEDS WHEN ACCESSING AOD TREATMENT SERVICES: SURVEY REPORT

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Designed, conducted and written by Edita Kennedy, Amelia Berg, Louise Goebel

Copy-edited by the APSU team

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Enquiries and comments about this report should be directed to:

Matthew Corbett, Manager – Lived Experience Workforce & Advocacy Association of Participating Service Users 140 Grange Road, Carnegie, VIC 3163. Phone: 03 9573 1776

Email: <u>apsu@sharc.org.au</u> Website: <u>www.apsuonline.org.au</u>

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Self Help Addiction Resource Centre (SHARC)

SHARC is a Victorian community-based not-for-profit organisation.

SHARC provide housing, education, advocacy and support to members of our community who have been impacted by the effects of AOD addiction or dependency.

SHARC works with families and individuals through a peer support model. Our team consists of people with the combination of lived experience and professional expertise.

Association of Participating Service Users (APSU)

APSU is the Victorian consumer representative body for people impacted by AOD related service delivery, policy and research.

APSU believes that people who use (or are eligible to use) AOD services have a wealth of knowledge and experience, and that their needs, strengths and expertise should drive the system.

APSU recognises the diversity and complexity of the community impacted by AOD issues.

APSU is membership based and its membership is free of charge.

APSU is a service of SHARC.

1 Introduction

It is important to create platforms for consumers to give feedback on services and policies that impact upon them, and for their voices to be heard. In December 2020, APSU conducted an online survey of service users and their family members or carers that focussed specifically on the lived experience of accessing or attempting to access AOD treatment services in Victoria. *Victorian Service Users' Experiences and Needs when* Accessing AOD Treatment Services: Survey Report is based on the 2020 survey. It describes the lived experiences of barriers to access and support needs as they were reported by respondents. This report can be read alongside other APSU reports, including Victorian AOD Service Users' Needs and Experiences during the COVID-19 Crisis: Consultation Report (2020) and Your Feedback Matters (2019).¹

Public-funded AOD services to which people seek access include a spectrum of clinical and non-clinical, community-based and residential treatment options. Services are delivered via treatment streams, including: counselling, non-residential withdrawal, therapeutic day rehabilitation, residential rehabilitation, care and recovery coordination and pharmacotherapy.²

Access to treatment streams requires a referral which can be initiated by contacting DirectLine, or local intake providers, and various health and human service providers including GPs. The catchment-based intake service system is designed to be the primary entry point into the public-funded treatment system. The idea is that centralised referral and intake services mobilise appropriate pathways into AOD treatment based on individual needs, including the needs of families and friends.³

Person-centred treatment is framed as a remedy for catchment-based limitations in accessing services. According to the Victorian Department of Health (DH) information:

¹ In 2018, APSU conducted a survey of service users and their families about their experiences navigating the Victorian AOD treatment system. The results were published in Your Feedback Matters in November 2019. See APSU (2019) Your Feedback Matters: a snapshot of consumer experiences with Victorian AOD services in 2018, Self Help Addiction Centre [SHARC]: Carnegie. This report can be accessed at http://www.sharc.org.au/wp-content/uploads/2020/10/Your-Feedback-Matters-2019-Survey-Report.pdf. See also APSU (2020) Victorian AOD Service Users' Needs & Experiences During the COVID-19 Crisis: Consultation Report, July 2020, SHARC: Carnegie.

² This information is taken from the Vic Health website. See Vic Health (2017-2020) Alcohol and other drug treatment services, <u>https://www2.health.vic.gov.au/alcohol-and-drugs/aod-treatment-services</u>, Victorian Government, viewed 1/11/21; Vic Health (2017-2020) Overview of Victoria's alcohol and drug treatment system, <u>https://www2.health.vic.gov.au/alcohol-and-drugs/aod-treatment-services</u>, Victorian Government, viewed 1/11/21; Vic <u>drugs/aod-treatment-services</u>, Victorian Government, viewed 1/11/21.

³ Vic Health (2017-2020) Overview of Victoria's alcohol and drug treatment system, <u>https://www2.health.vic.gov.au/alcohol-and-drugs/aod-treatment-services/aod-system-overview</u>, Victorian Government, viewed 1/11/21.

Person-centred treatment is a governing principle in the delivery of services. Clients may choose to seek intake services away from where they live. This means that access to alcohol and other drug services is not limited by catchment boundaries.⁴

Our survey respondents gave feedback that challenged this premise. As we will see, barriers to access include, but are not limited to, catchment boundaries.

This report passes on consumer insights into how policies that shape treatment access and service engagement are working. It also aims to give a constructive form to the survey findings by focussing on opportunities for improving the experiences and supports for service users and their families. We assume that successful outcomes of AOD treatment services are measurable in terms of the experience of service users, and approach their feedback as a rich source of expertise relevant to service design and sector reform.

1.1 Method

The survey was developed with consumer input from the APSU Advisory Committee. It was designed using Survey Monkey and contained a total of 17 questions asking respondents to select from a set of options, and give open-ended answers.

A cohort of 42 service users and family members responded to the online survey. Survey Monkey marks each respondent as "complete" or "incomplete". 29 respondents were categorised by Survey Monkey as having completed the survey, representing participants who responded to all of the questions. This report used quantitative results based on the total of "complete" surveys.

The first four (4) questions asked participants to identify their age and gender, whether they were a service user or a family member / carer, and where and when they accessed or attempted to access services. The next 12 questions focused on the respondents' experiences and support needs when accessing AOD treatment services. See Appendix 1 for a copy of the survey questions.

The final question offered participants the option to submit their name and contact details for entry in a prize draw. The survey responses of participants who declined to provide contact details were accepted and included in this report.

Participants were recruited in three ways:

- An email with a link to the survey was sent to APSU members on 22nd December 2020.
- The survey was advertised in the VAADA E-news Bulletin on 22nd December 2020.
- The survey link was posted on the APSU Facebook page on 23rd December 2020.

⁴ Ibid.

1.2 Limitations

The survey did not specifically address the barriers to access to services occasioned by the COVID-19 restrictions. A separate Consultation Report published by APSU in July 2020 called *Victorian AOD Service Users' Needs and Experiences during the COVID-19 Crisis*⁵, explored impacts of lockdowns and restrictions on treatment programs between March and May 2020. We still don't have a comprehensive picture of barriers to access for Victorian service users and family members and carers during the (ongoing) pandemic. It should be noted that disruptions created by the COVID-19 pandemic likely exacerbated barriers to access that already existed.

Second, the survey predated the now imminent roll out of integrated mental health and AOD services, following recommendations of The Royal Commission into Victoria's Mental Health System. These reforms will impact how service users and their families experience access to AOD services. This report includes feedback from people who have accessed or attempted to access dual diagnosis services.

Third, the survey was promoted and completed online, a significant limitation for those without access to, or with limited access to, the internet and/or data. The widespread closure of services, including public libraries, and the restrictions on mobility mandated by isolation rules, meant that the ability to participate in an online survey was dramatically curtailed for many.

Fourth, APSU acknowledges that only a small number of respondents were reached and cannot claim to give a comprehensive overview of barriers experienced in accessing or attempting to access AOD services. The small pool of respondents was shrunk further by the decision to exclude incomplete surveys from the analysis, resulting in a pool of 29 surveys out of a total of 42. The proportion of Female respondents decreased, after eliminating 12 (out of 13) incomplete surveys, from 71.43% to 62.07%. The proportion of Service Users increased from 76.19% to 82.76%. Half of the surveys submitted by Family Members / Carers were excluded. Incomplete surveys were submitted by all age groups, except 18-24. All except one (1) of the incomplete surveys were submitted by participants accessing services in metropolitan Melbourne.

Finally, some limitations relate to the design and clarity of some questions. Respondents who identified as Family Members and Carers had ambivalent directions for answering questions relating to gender, age and location. While the intention was to gather data about service users, some submitted their own information. Future surveys will refine survey questions.

This report nevertheless contributes to the pool of primary research that exists on the experience of AOD service users and their families in accessing treatment. For example, the challenges of long waiting lists is well-known. When our findings reiterate well-known themes it is a timely reminder that more work and resources are needed to improve access to AOD services.

⁵ This report can be viewed at https://www.sharc.org.au/wp-content/uploads/2020/10/COVID-19-Experiences-2020-Consultation-Report.pdf

APSU strives to contribute evidence from people with lived and living experience to make a case for improved access to services and supports. This report is part of that contribution.

2 Key Findings

This survey report focusses on the experiences of accessing services, the barriers to access and support needs of service users and their family members and carers. Key findings in *Your Feedback Matters* (2019, p5) continue to resonate: waiting lists are too long and services are often unavailable when they are most needed; the intake and assessment process can be convoluted and difficult to navigate; the requirement to repeatedly tell one's story in order to access a service is frustrating and often inexplicable; people experience significant stigma. All of these findings remain pertinent descriptions of barriers to access.

The report spends time analysing how barriers to access are interrelated, when one barrier co-exists with and exacerbates others. For example, the problem of long waiting list times is still a significant barrier to access, with too many people waiting to enter too few services, with little support.

I think there is a great need for more services to be available and for waiting time to be minimised generally in the AOD sector. We need more of all types of support and services.

Long waiting list times, experienced by 62.07% of respondents, is exacerbated by the lack of support while on waiting lists, experienced by 51.72%. Long waiting lists are not an isolated problem, and it impacts on the whole experience of access when treatment and support is needed in times of personal, social and economic vulnerability. Compounding this situation is the lack of information about services and treatment options.

The overall experience of difficulty in accessing AOD treatment services tends to increase for those who confront many barriers. Experiences are complicated when a service is sought that caters for a specific demographic group or treatment need.

In the light of the barriers to access that will be looked at in-depth in this report, respondents provided a clear path for mitigation, especially in the context of support needs. There is a demand for more community-based service options, including peerbased support. There is evidence that a stronger systemic presence of peer workers and peer-based services is needed and welcomed.

Feedback suggests that the experience of pathways into treatment services from the point of intake and assessment can be difficult. The multi-facetted person with layered life experiences is not always reconcilable with prescribed service entry points and treatment types. Respondents reported having co-occurring AOD and mental health treatment needs that weren't accommodated by services. They also reported that their social, psychological and economic conditions – housing work obligations, relationships, planning – were impacted by accessing AOD treatment in ways that weren't recognised by services.

This report tries to show how the complexity of individual treatment needs, and expectations, get lost or misunderstood in an under-resourced system. Entry into services can be lengthy and experienced without sufficient or adequate support. Assessing AOD services is even more difficult when there are co-existing mental health (dual diagnosis), or other health (chronic pain), issues. The problem of positioning consumers in appropriate treatment contexts is compounded by a scarcity of services, a lack of effective communication and, or training at key access points.

3 Demographic Profile of Participants

This section summarises the profile of 29 respondents who submitted completed surveys.

The first four questions were:

Q1. Are you completing this survey as:

Options: A family member or carer, Service User

Results:	
Service User	24 (82.76%)
Family member / Carer	5 (17.24%)

Q2. What gender do you or your family member identify as?

Options: Male, Female, Gender Diverse

Results:

Female	18 (62.07%)
Male	9 (31.03%)
Gender Diverse	2 (6.90%)

Q3. What age are you or your family member?

Options: Under 18, 18-24, 25-34, 35-44, 45-54, 55-64, 65+

Results:

Age 18-24	3 (10.34%)
Age 25-34	8 (26.59%)
Age 35-44	10 (34.48%)
Age 45-54	4 (13.79%)
Age 55-64	2 (6.90%)
65+	2 (6.90%)

Q4 Did you or your family member access or attempt to access AOD treatment services in a metropolitan area or a rural / regional area?

Options: Rural/regional, Metropolitan

Results:

Metropolitan	86.21% (25)
Rural / Regional	13.79% (4)

The table below gives a breakdown of the age, gender and location of respondents.

AGE	FEMALE / METROPOLITAN	FEMALE / RURAL & REGIONAL	MALE / METROPOLITAN	MALE / RURAL & REGIONAL	GENDER DIVERSE / METROPOLITAN	GENDER DIVERSE / RURAL &
						REGIONAL
18-24	1	1	1	0	0	0
25-34	4	0	3	0	1	0
35-44	6	0	2	1	0	1
45-54	3	0	1	0	0	0

55-64]	0	0	1	0	0
65+	2	0	0	0	0	0

3.1 Accessing AOD Treatment Services

Questions 5 and 6 asked when and how respondents accessed or attempted to access services.

Q5 When did you or your family member access or attempt to access AOD treatment services?

Results:

68.97% (20) of respondents reported accessing or attempting to access services in 2020, spread out over 12 months. In the months of March, July and August there were no reports of access.

January 2020	3.45% (1)
February 2020	6.90% (2)
March 2020	0.00%
April 2020	3.45% (1)
May 2020	13.79% (4)
June 2020	10.34% (3)
July 2020	0.00%
August 2020	0.00%
September 2020	3.45% (1)
October 2020	6.90% (2)
November 2020	6.90% (2)
December 2020	13.79% (4)

31.03% (9) reported access before January 2020. Two of these reported attempting to access services over a period of year, including 2020. The table below compiles the times specified by respondents who chose the option 'Before January 2020'.

2007	2016 to 2018	2016 - 2020
2017	2017 – 2020	January 2018
June – July 2018	1/11/2019	Most months

Q6 How did you or your family member access or attempt to access AOD treatment services?

Results:

I contacted my local area-based catchment intake service	27.59% (8)
I contacted the service provider directly	27.59% (8)
Other (please specify)	27.59% (8)
I contacted DirectLine	10.34% (3)
My GP referred me	6.90% (2)

Eight respondents (27.59%) selected 'Other'. The table below records their responses that pinpoint access occurring through health and social services, including forensic services.

Psychiatrist	rehab	Both local-area catchment and contacting service directly	I was admitted to hospital and got referred to the addiction specialist. I also have a GP who specialises in addiction.
All of the above	My community corrections order appointed AOD worker explored rehab options with me	Family Drug Treatment Court	My corrections worker referred me

Questions 7 to 9 asked for information about the kind of treatment services that were sought, including specific services.

Q7 What AOD treatment services did you or your family member access or attempt to access? (Please select all that apply)

Results:

In Question 7, a list of AOD treatment service types were listed from which respondents selected all options that applied. This list included Intake & Assessment which is a requisite step to access an AOD service. 55.17% (16) survey respondents selected Intake & Assessment, always alongside additional options.

Most respondents selected more than one option. The total number of times an option was chosen is reflected in the table below, listed from the highest to lowest percentage:

Counselling	82.76% (24)
Detox	62.07% (18)
Intake & Assessment	55.17% (16)
Residential Rehabilitation	34.48% (10)
Pharmacotherapy	27.59% (8)
Peer Support	17.24% (5)
Day Program	17.24% (5)
Dual Diagnosis services	17.24% (5)
Supported Accommodation	6.90% (2)
Care & Recovery Coordination	6.90% (2)
Other	6.90% (2)

Two respondents selected 'Other'. They recorded SMART Recovery, and medication recovery services (pain management), as services they sought to access.

Q8. Did you or your family member require a service that specifically catered to the following? (Options included: Aboriginal and Torres Strait Islander, LGBTIQA+, Youth, Culturally and Linguistically Diverse, Disability, Religion, Other, None of the Above) Results:

44.83% reported seeking an AOD treatment service that specifically catered to a demographic grouping.

LGBTIQA +	13.79% (4)
Youth	13.79% (4)
Disability	10.34% (2)
ATSI	3.45% (1)
Culturally & Linguistically Diverse	0
Religion	0
Other	10.34% (3)

Note: One (1) respondent nominated two specific types of service needed, for ATSI and LGBTIQA+. Respondents who selected 'Other' identified specific treatment needs, including trauma, mental illness and mental health.

Q9 Were you or your family member successful in accessing this specific service? Results:

Of this cohort seeking AOD treatment services that catered for specific needs, 46.15% (6) reported they were successful in accessing the service they required; 30.77% (4) were not successful; and 23.08% (3) were partially successful.

The results of Question 10 are discussed in detail in the next section.

Q11 How long did you or your family member have to wait to receive the service you were trying to access?

Results:

All respondents reported the length of time that they waited before receiving a service they were trying to access. The results are listed in the table below.

Up to one week	21.43% (6)
Between one week and one month	32.14% (9)
One to three months	32.14% (9)
Three to six months	7.14% (2)
More than six months	7.14% (2)

3.1.1 Observations on Selections of AOD Treatment Service Options

Most respondents selected more than one service option in Question 7.

Four (4) respondents selected only ONE service option, either Counselling, Residential Rehabilitation, or Care and Recovery Coordination. All accessed a service in the metropolitan area.

Eight (8) respondents selected TWO service options. Three (3) in this group sought access from a Rural / Regional area, and selected counselling as an option. All sought to access community-based services, including Intake and Assessment, Counselling, and Day Program.

Six (6) respondents selected THREE service options. Counselling and Detox were both represented in all of the combinations of three service options. Four (4) were seeking a specific service or treatment type. And all sought access in the metropolitan area.

Six (6) respondents selected FOUR service options. All sought access in the metropolitan area. A combination of residential and community-based services were present in all of these clusters.

Two (2) respondents selected SEVEN service options. Their respective experiences provide a significant contrast. One, a female aged 65+, whose GP referred her to services, which she waited between 1 week and 1 month to access. She accumulated a positive experience with treatment services over 3 years, and rated her overall experience as EASY. She gave this feedback:

I am so grateful for your support. The services and ongoing counselling are a very important part of my life. Thank you.

The second respondent, a female aged 25-34, who (unsuccessfully) sought services specific to her ATSI and LGBTIQA+ identity, and who also waited between 1 week and 1 month to access a service, rated her overall experience as DIFFICULT. Her direct feedback was brief but to the point:

More easily accessed. More affordable.

The difference in their service options was the selection of Peer Support in the first case, and Dual Diagnosis in the second case. There was a drastic difference in their overall experience of barriers to accessing services.

The single respondent who selected EIGHT options gave a lot of feedback relevant to their history of attempting to access services, which spanned three years and was current. They said:

I have been attempting to get adequate treatment.

and I applied for many services.

Their treatment and service needs are complex, requiring medication recovery, pain management, and trauma-informed practice. This respondent waited up to 6 months to enter a service and rated her overall experience as VERY DIFFICULT.

4 **Experiences of Difficulties Accessing** AOD Treatment Services

This section evaluates the difficulties experienced in accessing treatment services. It considers the combination of and interaction between difficulties. By looking at the interactions we can get a better view of the problem of long waiting list times.

Q10. What difficulties did you or your family member experience when accessing AOD treatment services? (please select all that apply) Results:

Respondents were asked to identify difficulties from given a range of options. They could also specify other difficulties that were not listed. The ranking of difficulties is presented below, in order of the most selected difficulty to the least selected difficulty.

62.07% (18)
51.72% (15)
51.72% (15)
48.28% (14)
34.48% (10)
31.03% (9)
31.03% (9)
27.59% (8)
27.59% (8)
27.59% (8)
24.14% (7)
24.14% (7)
24.14% (7)
24.14% (7)
17.24% (5)
17.24% (5)
13.79% (4)
10.34% (3)

Other difficulties were described by respondents in both Question 9 and Question 10. In one case the difficulty is a straightforward case of lack of service resources:

Found a service but [they] were too busy to help at the time.

One respondent explained why they experienced financial barriers to entering a three month residential rehabilitation service. This service user accessed the service with the help of a Community Corrections Order appointed AOD worker, and waited 3 to 6 months to enter the rehab. She describes how entering a residential service impacted on her precarious economic and housing situation:

In order to enter into 3 month residential rehab which takes up to 75% of my income I had to give up my current accommodation being a cabin in a caravan park. Which meant finding somewhere to store all my belongings and potentially walking out of rehab homeless. Which could have me worse off.

This respondent had to enter a long term rehab when they were excluded from another service because they were on a Suboxone program:

I was originally on a wait list for a different 8 week rehab short circuit but after waiting a couple of months they then advised I would not be able to attend that rehab as I was on the Suboxone program so me and [my AOD] worker had to find another [suitable rehab].

Another response also described prerequisites for entering a residential rehabilitation service as serious burdens:

Residential rehabs expect you to drop your entire life for months up to a year after a long wait at a moment's notice.

Another kind of financial barrier was experienced by a respondent who needed affordable AOD counselling. They were on a reduced income, without a health care card, and participating in a mental health treatment plan. These factors were barriers to accessing AOD treatment. At the time of participating in the survey, this service user was still looking for an AOD counselling service she could afford to use:

Trying to access free/cheap counselling not having a [health care card], but have decreased work hours has been difficult. Already having a Medicare Mental Health plan and seeing an ongoing general [psychologist] has I believe made this process harder.

A service user from a rural / regional area reported on the barriers in the convoluted referral process. They were unable to get a direct referral to a mental health-specific counselling service they preferred, and settled with another for the sake of ease:

I wanted to access a different service, but was told I would need a referral from the service who ended up giving me treatment. It all seemed to difficult, as a direct referral apparently wasn't allowed. In the end I just went with who they said was available.

Pathways to treatment services can be disrupted by practical and financial pressures, as well as by the co-existence of treatment needs. Undergoing treatment in one place can hinder access to treatment in another. In one case the respondent couldn't access a mental health service (a psychiatrist) until they had accessed an AOD service (a detox).

Co-existing health issues were identified as a barrier to accessing AOD services by several respondents. Complex co-occurring treatment needs proved a significant and ongoing barrier for one respondent (who identified 12 difficulties in Question 10 as well as giving detailed feedback). Her case reveals how barriers to access are compounded when complex treatment needs meet current systemic arrangements for accessing AOD services:

Lack of collaborative treatment for chronic pain, trauma, medication recovery (managing prescribed medication - taken as prescribed but causing adverse effects and wanting to taper off. Services were confused where to place this as it didn't meet criteria for drug disorder but still needed similar support).

4.1 The Experience of Waiting Lists

While 62.07% of respondents reported long waiting list times among the difficulties they experienced when attempting to access AOD treatment services, 53.57% waited between 0 days and one month before entering a service. To put this into perspective it is worth looking in more detail at those that didn't nominate long waiting lists as a difficulty, which includes 11 respondents. This group has the following features:

- Includes 5 (out of a total of 6) respondents who waited up to one week to access a service, and 5 (out of a total of 9) who waited between one week and one month
- All 4 respondents who selected "None of the above" in Question 10 are in this group
- A respondent who was unable to get on a waiting list is in this group
- 8 in this group sought Counselling, including 6 who selected Counselling only or with one other option in Question 7
- 5 in this group were already engaged in a health or AOD treatment service (including a rehab, hospital or GP), or forensic services. A drastic example of a waiting list being shortened due to engagement with a health service is to access an AOD service via hospital emergency. In this case the respondent waited up to 1 week to enter detox because of the severity of her situation:

I was transferred to a detox as an emergency case after being in hospital three times in a month

4.2 The Experience of Difficulties When Undergoing Intake and Assessment

Some difficulties listed in Question 10 relate to the experience of undergoing the process of Intake and Assessment. These include:

Having to repeat my story numerous times	51.72% (15)
Lack of information about what services are available	48.28% (14)

Stigma and discrimination	31.03% (9)
Confusing intake and assessment system	24.14% (7)
Privacy concerns	24.14% (7)

The top two difficulties relate to an uneven flow of information, and the power imbalance in the relationship between the respondent and assessor. The experience of difficulties in having to repeat their stories numerous times, to different people, could be compounded or exacerbated by the lack of information about services that is returned. Of the 15 (51.72%) respondents who selected 'Having to repeat my story numerous times' as a difficulty, 12 also selected 'Lack of information about what services are available'. The frustration of having to repeat stories might be heightened when there is a lack of reciprocity with little information exchanged.

A family member / carer, gave this feedback about their experience:

My husband told his story of addiction to many workers, with whom I am unsure what the purpose was as there was no follow up or tools given for him to address what was happening. It triggered him and at times, made his healing feel too raw to bear.

The relationship between service users and assessors is distorted by power imbalance in another way: when workers lack, or display a lack, of empathy and understanding. One respondent said they would like to access services without lengthy assessments and that:

In some assessments I've experienced the assessor didn't really care or seemed to be judging.

31.03% of respondents reported experiencing stigma and discrimination. Of these 9 respondents, 8 selected both 'Stigma and discrimination' and 'Having to repeat my story numerous times'. There may be no direct causal relationship to be found, but the point here is to consider their connectedness, especially in the Intake and Assessment process.

Of the seven respondents who selected 'Privacy concerns' in Question 10, five (5) also selected 'Having to repeat my story numerous times'. Service users are required to provide confidential personal information, repeatedly, with little information about services in return. People are asked to tell their stories repeatedly, in cumulative interviews, and they are also asked to consent to the passing on of that information to other agencies. Again, it's worth considering whether the frustration of having to repeat stories is magnified when there isn't a fair exchange of information.

Nearly a quarter of respondents identified 'Confusing intake and assessment system' as a difficulty in accessing treatment services. Of the 7 participants that selected this option, 5 had accessed or attempted to access services via their local area-based catchment intake services. Four of these attempted access during 2020.

The experience of a confusing intake and assessment systems is likely made worse when there is a lack of information about what services are available which erodes the ability to make an informed choice about treatment service options.

4.2.1 The Experience of Difficulties with Service and Treatment Options

Lack of information about what services are available	48.28% (14)
Conflict with work, study or parenting responsibilities	34.48% (10)
Limited access to services out of business hours	31.03% (9)
I needed to meet specific criteria / pre-requisites to be accepted	27.59% (8)
Financial barriers	27.59% (8)
Services expected abstinence only	27.59% (8)
Lack of services in my area	24.14% (7)
Services didn't cater for my needs	24.14% (7)
Lack of autonomy and power in making treatment decisions	17.24% (5)
Services expected me to be part of 12-step programs	10.34% (3)

The experience of difficulties with service and treatment options varies from the general to the specific. We have already highlighted the importance of the 48.28% who experienced a lack of information about available services. A paucity of information adds to layers of difficulties in accessing services. Lack of information disempowers people from making informed decisions that take into account the nature of their life situations, including work, study or parenting responsibilities, personal relationships, finances, housing, mobility and social capital.

There are also difficulties that relate to the nature of AOD service structures, including their location, opening hours, prerequisites, scope and professional capacity to deal with a range of AOD problems.

One respondent doubted that AOD workers had sufficient knowledge, training or resources to help them access the treatment services appropriate to their needs:

Some service providers... lacked knowledge of mental health/dual diagnosis. They simply were not trained well enough. Lack of funding for services to provide adequate care.

A family member / carer was critical of treatment options and approaches adopted in a youth service:

Not listening to the young person because fixed on particular method. Inconsistency of philosophy within organisations... Lack of flexibility in treatment... Youth workers [have] difficulty with maintaining relationships with young person if they showed (understandable and predictable) resistance or ambivalence.

This participant also reported difficulties being unsupported as a family member by the service:

Resistance to engaging with and including family. Dislike of family support in getting young person to appointments etc. Family members can conflict with service workers if they perceive a lack of flexibility or engagement. This is difficult for services who must prioritise the needs and privacy of their clients. Undoubtedly it is challenging for services to juggle the needs of the young person and the family. The survey focussed on the difficulties experienced by those with AOD treatment needs, so it is enough here to flag that this sort of conflict with family occurs.

'Conflict with work, study or parenting responsibilities' and 'Limited access to services out of business hours' were experienced as difficulties in 19 instances. Three people selected both of these options as a difficulty while others selected one or the other. In total 16 respondents reported one or both of these options as a difficulty. Four of these respondents were Family Members / Carers, only one of which selected both options.

'Services expected abstinence only' was selected as a difficulty by 8 participants. We can make some observations about this. For some respondents, the expectation of abstinence seemed unrealistic or overwhelming. One family member / carer thought the expectation of abstinence produced the risk of relapse because it was so "deficit-focused". In this case, there was a 1-3 month waiting period to start counselling. Another family member / carer reported:

The organisation says it supports harm minimisation but individual workers push for abstinence.

Half (4) of the participants who selected 'Services expected abstinence only' as a difficulty were seeking to access pharmacotherapy (amongst other service options). Five (5) also reported experiencing stigma and discrimination as a difficulty in accessing services.

On a final note relating to difficulties experienced with accessing service and treatment options, one respondent said they found it easy to access services (in 2019), essentially because they'd done it before:

I found it easy to access treatment as I have done it several times before in the past but for others if it was their first time it's very hard to know what to do and who to call.

This feedback supports the view that a 'lack of information about what services are available', reported by 48% of respondents, is a real barrier to accessing AOD services. It seems to contribute to layers of difficulties. It disempowers people from making informed decisions that take into account the nature of their life situations, and aggravates relationships between those who use AOD services and those who work in them.

5 Experience of Support When Accessing AOD Services

Q12. What support were you or your family member offered while on a waiting list? (please select all that apply)

In Question 10 "Lack of support while on waiting lists" was selected by 51.72% (15) as a difficulty in access to AOD services. In Question 12 respondents were asked to nominate what support they were offered while they were on a waiting list. Six (6) options were offered as well as the opportunity to select 'Other'. The results of responses are ranked below from the highest to lowest percentage:

I was not offered support while on a waiting list	50.00% (14)
Other (please specify)	25.00% (7)
The service checked in with me regularly to see how I was going	21.43% (6)
I was given information about harm reduction while on the waiting list	17.86% (5)
The service referred me to a local support group (AA/NA/SMART Rec)	10.71% (3)
The service gave me regular updates on my status on the waiting list	7.14% (2)
The service referred me to a peer worker for support	7.14% (2)

A quarter of the respondents selected 'Other'. A summary of these responses follows.

Two of these also selected "I was not offered support while on the waiting list". Both were drawing on supports in other sectors. The first of these reported:

I received some updates about allocation of a counsellor, and I was accessing support including some outreach support though my housing caseworker.

The second said:

I was still engaged in fortnightly appointments with [community corrections appointed] AOD support worker whilst on wait list for rehab.

Another reported they were "already engaged with support in the community", but didn't specify the support.

And another reported that they attended counselling while on the waiting list. (They indicated in Question 7 they were seeking to access counselling, detox and residential rehabilitation). In this case they could access counselling before they could access detox and / or residential rehab.

One respondent entered detox via hospital. This is a particularly dramatic example of how people already engaged in a support service are able to transition to an AOD service, though this is far from ideal.

I was transferred to a detox as an emergency case after being in hospital three times in a month.

Therefore, even though 50% of respondents reported they were not offered support while on a waiting list, it does not follow that none had access to support. Some had the support of allied health and social services which supported the transition into AOD treatment services. Others sought access to multiple services and were able to access one before others.

Furthermore, the lack of support does not determine the level of difficulty experienced in accessing or attempting to access services, just as the offer of support did not mitigate the experience of difficulties. In the case of people who were not offered support while on the waiting list, 6 rated their experience as either Somewhat Difficult (2), Difficult (2), or Very Difficult (2). Of the respondents who were offered support, 6 selected Difficult, while 1 reported Somewhat Difficult.

Two participants selected both "I was not offered support while on the waiting list" but reported their overall experience as Somewhat Easy. Both had the support of workers in housing and community corrections. Another rated their overall experience as Very Easy but reported they were not offered support on the waiting list.

We saw in the results from Question 10 that 50% (14) of people nominated "Lack of support while on waiting lists". Eight (8) of these nominated "I was not offered support while on the waiting list". Five (5) were offered some form of support (indicated in Q12) yet they still identified lack of support as a difficulty in Question 10. The range of supports these respondents nominated having received included:

The service referred me to a local support group.

I was given information about harm reduction while on the waiting list.

The service gave me regular updates on my status on the waiting list.

The service checked in with me regularly to see how I was going.

Therefore while supports are offered they are not necessarily experienced as supportive. A family member / carer gave feedback on the quality of the support their loved one received while on a waiting list for a counselling service. They thought those check-ins had a negative impact:

There were 'check in's which involved them asking the client whether they had used / drank since the last time, and pretty basic information. Every time he spoke to a person who asked about all the negatives, he felt like another drink / relapsing and wasn't given any tools to assist him in those moments. It was very deficit focused, rather than strengths based which would and does help him much more. Especially when it was the first time he has sought support for a 20 year addiction. In this case it's possible that the family member / carer also experienced a lack of support while their loved one was on the waiting list.

5.1 Support Needs of People Accessing AOD Services

Q13. What would have assisted you or your family member while you were on a waiting list?

Results:

Regular updates from the service about my status on the waiting list	76.92% (20)
Information about harm reduction and risk management	53.85% (14)
Referral to an outreach worker	53.85% (14)
Referral to a peer support worker	50.00% (13)
Referral to peer support groups (AA/NA/SMART Recovery)	34.62% (9)
Other (please specify)	19.23% (5)

Questions 14 and 16 invited open comment: 26 people gave feedback in Question 14, and all 29 respondents gave feedback on Question 16.

Q14. What would you or your family member like to see change in how AOD treatment services are accessed?

A family member / carer wrote "All of the above" in the "Other" field. They also reiterated the difficulty of repeating the story, a matter for concern even once a person is on a waiting list. This respondent thought that follow up support calls should not require the service user to repeat their story:

All of the above. Tools to address triggers when not able to seek support, or even a line to call when feeling distressed where he doesn't have to explain his situation from the beginning every time.

Another, a service user, commented "*None of the above*" in the "Other" field. This respondent entered a private AOD service.

Another specified "outpatient groups" in the "Other" field. They also selected "Referral to a peer support worker" and "Referral to an outreach worker".

A service user seeking access to a mental health-specific counselling service in a regional / rural area, explained how the frustration with the long waiting list was compounded by unreliable service updates, and the lack of substantial support. They tried to initiate a conversation about interim supports, but received minimal directions:

I think being told what the procedure was, in terms of the expected wait, didn't really help. It was extended beyond what they said and I just assumed that's how it worked. I did make contact with them myself, I think on two occasions, but nothing was ever offered as to try this in the interim. I was given the usual phone numbers at the first of two assessments... But this is really what I consider the bare minimum.

Another family member / carer reported their husband received regular check-ins and was unimpressed with the support:

More support and understanding to meet him where he is at, while assisting to develop new coping strategies and distractions when it comes to his alcohol use.

The combination of long waiting lists and uncertainty conspire to cause frustration and risk of relapse for those seeking to access treatment services.

The feedback below is a reminder that people seeking access to AOD services, especially residential services, have to juggle work, family, housing and other responsibilities:

More clarity about wait times for detox or rehabilitation facilities... to organise around work and other responsibilities.

One respondent raised the need for more contact and more information on waiting times from a parenting perspective:

More consistent contact in wait list times and what that really means from a reporting perspective parenting wise. All options on the table.

Several made general statements about the need for more supports while on waiting lists. One said:

Easier access to support workers and support in general while waiting for intake.

And another):

More contact from provider while client on waiting list.

In a related vein, a service user found the stress of a long waiting list exacerbated by having no information about the residential service they were to enter. They gave this feedback:

More Information about the rehab as there was no [information] session. The more I knew what to expect the less anxiety and less chance of cold feet. A similar theme was raised by another respondent (#32):

There needs to be greater support for the uncertain wait time for detox, counselling etc.

This problem of leaving people in limbo on waiting lists, without a trusted support person or network in their community, is summed up neatly by one respondent:

I just think that there needs to be a focus on supporting people whilst they wait, it's not good enough that there's nothing offered apart from Lifeline et al.

Another talked about support on a continuum:

More support before and after detox and more to do well in detox.

5.2 Community-based Support and Peer Support

Community-based treatment options help minimise disruptions in people's lives, and are flexible enough to allow for work, study and parenting, or for home-based treatment.

The desire for community-based supports is strong, and is related to stressful waiting times that are so often experienced by vulnerable people with pressing treatment needs. There were 36 instances of selecting options for support based in the community. These 36 selections were made by 18 respondents.

Referral to an outreach worker	53.85% (14)
Referral to a peer support worker	50.00% (13)
Referral to peer support groups (AA/NA/SMART Recovery)	34.62% (9)

One respondent, who sought access to counselling in April 2020, selected "Referral to peer support groups". At that time, AA, NA and SMART Recovery groups were moving their meetings online in the first wave of COVID-19 lockdowns. People may have needed more support to access them. This respondent exited a counselling service in the lockdown, and needed to repeat the intake and assessment process. They describe their experience:

At the beginning of lockdown my final episode of counselling was delivered over the phone. I was scared I would lapse soon, but was no longer able to extend the episodes of counselling and was discharged from the service, which meant that when about 3 weeks later I lapsed and needed more AOD support I had to begin again with a new intake and then wait about a week till I had an appointment for comprehensive assessment and then wait another one to one and a half weeks or so until a counsellor was allocated and an appointment was made. Eight (8) respondents selected both 'Referral to a peer support worker' as well as 'Referral to an outreach worker'. Another two (2) respondents selected both 'Referral to a peer support worker' and 'Referral to peer support groups'. Three (3) selected all of these options. This represents evidence of the demand and need for community-based support services, especially for peer-based support services.

Two respondent said there should be more and better resourced peer support services; that there is room for:

Funded [peer support and] more knowledge about what peer support is.

Another reflected on how valuable peer supports groups are and wished they had found out about them earlier, especially when waiting to access a detox service. They did not get this information in the intake and assessment stage:

I found out about "SMART RECOVERY" meetings well after my home detox. I was only told about this meeting through my support worker, which was well after detox had finished! I love the meeting I attend & think it would have been a really valuable support to have known about whilst waiting for home based detox.

In this case support may have come in the timely provision of information and encouragement to access supports in the community.

Community-based support services, including self-help groups, 12 step groups, peer support, and outreach work, all have the potential to support people on waiting lists.

6 Additional Feedback on Access to AOD Treatment Services

Q16. Is there anything else you would like to tell us about your experience accessing or attempting to access AOD treatment services?

The feedback offered another set of responses related to complicated and lengthy referral processes.

Respondent #1, a service user in a rural / regional area seeking to access Intake and Assessment, and Counselling, via the local area-based catchment intake service in June 2020, had difficulties related to the incidence of multiple referrals involved in their case:

I think it's access, as in choice of who you want to see and direct referrals. I don't know why I need to be referred by another organisation or two in the case of one service.

For others access to services is seen as too complicated in a general sense, as one respondent seeking a youth-specific service did:

Easier access and less requirements / prerequisites.

One respondent suggested the panacea of "A one stop shop".

Another, however said:

Not everyone wants to go through a central intake & assessment process.

A suggestion from another:

Make it easier to contact the services directly.

Another nominated:

Being able to access services without lengthy assessments.

Another specifically mentioned minimising the need to repeat their story:

Not having to talk to numerous people and retell my story.

Another theme relates to both waiting times and affordability. Respondent #1, from the perspective of a rural / regional service user, said:

Also, the waiting time is ridiculous, it's typical of most government services, you can pay for direct access, but I'm not in that position.

Another:

More easily accessed. More affordable.

This raises the more specific point about access to publicly-funded AOD services:

More access to public rehab as the cost for my treatment privately was \$40,000.

It hardly needs to be said, but participants repeated the stark need for "*more facilities*", including specific service options, "*more youth focussed options*". Financial barriers alone do not make accessing services difficult, but also the range of treatment options. Respondent #12 said this:

Not all treatment services are suitable for everyone. What may work for one person may not be suitable for the next.

Like respondent #37 who thought access should be supported by "a more open and *flexible service*", respondent #12 imagined this could be done by taking more account of people's circumstances:

Take things like medication, current accommodation into account as it may be the reason a client doesn't seek treatment.

However a respondent (#32) who was getting information about harm reduction while they were on the waiting list gave this feedback:

I feel that it was a bit of an ask to attend daily check-ins that were really a waste of energy & time needed to detox & look after yourself as well. Bring back the days when in home, meant just that! It made a huge difference having the nurse visit you in the safety & comfort of your own home. I guess it was more engaging & less overwhelming than having to catch public transport etc., to the service for 15-30mins. When in early detox, being in stressful situations can stir up many triggers that are not necessary.

The need for more specific services was raised, including more youth services and complex cases:

Increased number of services that do long term work with young people. Increased residential services for complex people.

From another angle, respondent #14 said:

Wait times need to be lower so more places within services. Perhaps a wider range of services catering for lower risk cases as well.

Another (#39) suggested there be more support from "harm reduction framework services" and "dual diagnosis", and another (#19) commented "dual diagnosis services are very hard to access". The need "to open more detox stabilisation places" was also mentioned (#29).

Respondent #27 expands on the need for more treatment services, including detoxes, that are able to address complex needs, take into account drug and alcohol issues as well as mental health issues, including trauma-specific treatment services:

Integrated treatment models that provide service for drug and alcohol alongside mental health... The dual diagnosis models place too much emphasis on drug use and not enough training in trauma recovery. Need access to inpatient evidence-based treatment for trauma alongside withdrawal⁶. [T] here should also be pain management as well in rehabilitation detox services.⁷

⁶ They were very specific about their recommendations: "E.g Schema therapy, EMDR, DBT, ACT. These groups should be at a min 28 days long"

⁷ Again they were specific: Physios, exercise, detains, pain counselling, medication recovery and support, more information on alternatives to addictive pain meds (Ketamine infusions, Medical cannabis).

The same respondent pointed to range of skills and an interdisciplinary framework that is currently absent from the AOD sector, and that would accompany effective integrated services:

Drug and alcohol needs far better integration and training in trauma, mental health, pain management, poverty, discrimination -- needs to be more holistic collaborative care.

They offered additional feedback about what effective treatment services would look like:

Services should be easy and quick to access, therapeutic, homely (not hospital like), and have adequate mental health support whilst treating drug dependence symptoms. Drug dependence doesn't happen in a vacuum so there is no point to public detox except to park you there to withdraw ... There should be more autonomy in accessing a clinic you can get leave from and access the services mentioned, Psychiatrists should be seeing you daily, you should be seeing a psychologist regularly.

Their account of existing collaborative care practice suggests there is an enormous potential for renewal and reform in this area:

I accessed [what] claimed to be a collaborative care model but all I got was a weird counsellor who pushed his own views of religion on me and then harassed me for appointments after I stopped seeing him. He did utterly nothing to provide collaborative care. It baffles me that this one counsellor who was not well trained was meant to be providing 'collaborative care' for me.

Another theme that emerged concerned the lack of synchronicity between actively seeking AOD treatment services and their availability. In other words, services are not available when they are needed. This is significant for understanding the nature of the barriers posed by lack of services and long waiting lists.

Respondent #18 points to the benefit of shorter waiting lists is to give AOD services a better chance of providing an effective intervention:

Reduced wait times so services available when people are motivated to act.

Respondent #32 points out that when treatment is sought it is crucial there is a service response:

When you call a service & are ready to for example detox of your own will, (not for court reasons etc.), you need the help straight way.

Finally, participants continue to experience of stigma and discrimination while accessing or attempting to access services:

Less waiting times and more compassion.

Less judgement and stigma.

Less shame and fear I'm reaching out.

Respondent #27 accounted for circumstances where they felt degraded, patronised and stigmatised:

Services shouldn't be strip searching or treating service users like naughty children, or criminals... My drug disorder stems from trauma and pain. Without addressing that there is no point to the stigmatising paternalistic services currently on offer.

7 Conclusion

Access to services is often a lengthy process and is experienced without adequate support. The report evaluated difficulties experienced in accessing treatment services and considered the interaction between barriers.

The main barrier to accessing services, reported by 62.07% of participants, was "Long waiting list times". It was suggested that long waiting lists are exacerbated by a "Lack of support while on waiting lists" (experienced by 51.72%). The problem of long waiting lists is connected to a broader experience of service shortfalls in times of personal, social and economic vulnerability. Difficulties in the overall experience of accessing AOD treatment services tends to increase for those who confront many barriers. And experiences are complicated further when a service is sought that caters for a specific demographic group or treatment need.

It was also suggested that the barrier posed by "Having to repeat my story numerous times", reported by 51.72%, is compounded by the "Lack of information about what services are available" (48.28%). A paucity of information around treatment and service options adds to layers of difficulties in accessing services. Lack of information disempowers people from making informed decisions in the context of their individual life situations.

There is feedback to suggest that pathways into treatment services from the point of intake and assessment can be difficult to navigate. The multi-facetted person with layered life experiences is not always reconcilable with prescribed service entry points, catchments and treatment types. Some respondents with co-occurring AOD and mental health treatment needs weren't accommodated by services.

Survey results and feedback also tells us that social, psychological and economic conditions in individual lives – relationships, housing, work, health –impacted access to AOD treatment in ways that aren't acknowledged by services or policy makers. The complexity of individual treatment needs and expectations is minimised in an under-resourced system.

The problem of positioning individuals in appropriate treatment contexts happens in the context of scarce resources, but is compounded by a lack of effective communication and training for workers at key access points.

When individuals and their loved ones encounter barriers to accessing AOD services the impact on them and their treatment needs are costly in many ways. The outcomes might be entrenched poverty, poor health, distorted life trajectories and reduced social connection. It is unfortunate that barriers to accessing AOD treatment services is contributing to those problems, as much as AOD services strive to be part of the solution.

Participating service users and family members and carers provide a clear path for mitigating service gaps. There is a demand for more community-based service options, including peer-based support. The survey findings provide evidence for a demand for more peer workers and peer-based services, especially in providing support for those waiting to enter treatment. Peer-based support, available in the community and in services, would provide an invaluable resource for people needing, and waiting to enter, AOD treatment services. In turn, the provision of peer-based support services could help reduce other barriers to access, including stigma and discrimination, and lack of information and support while waiting to access services.

8 Appendix 1: Service Users' Experiences and Needs When Accessing AOD Treatment Services

Q1 Are you completing this survey as a:

- A family member or carer
- Service user

Q2 What gender do you or your family member identify as?

- Male
- Female
- Gender Diverse

Q3 What age are you or your family member?

- Under 18
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

Q4 Did you or your family member access or attempt to access AOD treatment services in a metropolitan area or a rural/regional area?

- Metropolitan
- Rural/regional

Q5 When did you or your family member access or attempt to access AOD treatment services?

- January 2020
- February 2020
- March 2020
- April 2020
- May 2020
- June 2020
- July 2020
- August 2020
- September 2020
- October 2020
- November 2020
- December 2020

• Before January 2020 (please specify)

Q6 How did you or your family member access or attempt to access AOD treatment services?

- I contacted DirectLine
- I contacted my local area-based catchment intake service
- I contacted the service provider directly
- My GP referred me
- Other (please specify)

Q7 What AOD treatment services did you or your family member access or attempt to access? (Please select all that apply)

- Intake and Assessment
- Counselling
- Detox
- Residential Rehabilitation
- Peer support
- Care and Recovery Co-ordination
- Pharmacotherapy
- Dual diagnosis services
- Day program
- Supported accommodation
- Other (please specify)

Q8 Did you or your family member require a service that specifically catered to the following?

- Aboriginal and Torres Strait Islander
- LGBTIQA+
- Youth
- Culturally and Linguistically Diverse
- Disability
- Religion
- None of the above
- Other (please specify)

Q9 Were you or your family member successful in accessing this specific service?

- Yes
- No
- Partially successful (please specify)

Q10 What difficulties did you or your family experience when accessing AOD treatment services? (please select all that apply)

- Long waiting list times
- Lack of information about what services are available
- Confusing intake and assessment system
- Lack of support while on waiting lists
- Lack of services in my area
- Having to repeat my story numerous times
- Services didn't cater to my needs
- I needed to meet specific criteria/pre-requisites to be accepted
- Lack of autonomy and power in making treatment decisions
- Services expected me to be part of 12-step programs
- Services expected abstinence only
- Limited access to services out of business hours
- Conflict with work, study or parenting responsibilities
- Stigma and discrimination
- Privacy concerns
- Financial barriers
- Other (please specify)
- None of the above

Q11 How long did you or your family member have to wait to receive the service you were trying to access?

- Up to one week
- Between one week and one month
- One to three months
- Three to six months
- More than six months

Q12 What support were you or your family member offered while on a waiting list? (please select all that apply)

- The service checked in with me regularly to see how I was going
- The service gave me regular updates on my status on the waiting list
- The service referred me to a local support group (AA/NA/SMART Recovery)
- The service referred me to a peer worker for support
- I was given information about harm reduction while on the waiting list
- I was not offered support while on the waiting list
- Other (please specify)

Q13 What would have assisted you or your family member while you were on a waiting list? (please select all that apply)

- Referral to a peer support worker
- Referral to an outreach worker
- Referral to peer support groups (AA/NA/SMART Recovery)
- Regular updates from the service about my status on the waiting list
- Information about harm reduction and risk management
- Other (please specify)

Q14 What would you or your family member like to see change in how AOD treatment services are accessed?

Q15 How would you rate your experience accessing or attempting to access AOD treatment services?

- Very easy
- Easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Difficult
- Very difficult

Q16 Is there anything else you would like to tell us about your experience accessing or attempting to access AOD treatment services?

- No
- Yes (please specify)

Q17 Contact details for prize draw. Participants' identities will be kept confidential. You do not need to provide these details if you do not want to.