

The 'Missing Middle' **Lived Experience Perspectives**

Identifying why people slip through the gaps or
do not receive the mental health care they need



Lived Experience
A U S T R A L I A

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Lived Experience Australia wishes to acknowledge and thank all the consumers, families and carers for speaking the truth of their experiences of engagement and disengagement associated with mental health services and supports. Having the courage to tell us about the barriers and how they found their own solutions has enabled us to gain a better understanding of their experiences with mental health services across Australia.

This detailed survey enabled us to have a better understanding of the 'missing middle' and what that means for people, beyond just a term. How consumers', families' and carers' lives are affected has been captured in this ground-breaking national survey, a first of its kind in Australia.

This is the first robust data from a lived experience perspective that will be made available in a desire to inform policy and service reform, particularly service design, planning, implementation and evaluation.

Lived Experience Australia wishes to thank Ms Christine Kaine and Professor Sharon Lawn, who carefully and independently translated the data and created this report.

And finally, we would also like to acknowledge the following people for their input into the development of this survey:

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Foreword

Lived Experience Australia (LEA) conducted a national survey covering a three-week period from 12 October 2020 – 2 November 2020 distributed through LEA's data base and social media as well as to other consumer and/or carer organisations with 535 people entering the survey. What makes these 'Missing Middle' collective reports different from others, is this is the first survey of its kind to seek and reflect the perspectives of both consumers AND carers about engagement and disengagement from mental health supports and falling through the gaps. Furthermore, it is the only survey which explicitly asked why people disengage and what it would take for them to re-engage with mental health services.

I am proud that LEA has been the vehicle through which people with lived experience have been able to contribute to this ground-breaking analysis of the 'Missing Middle', a term which is gaining popularity, but which in reading the many powerful comments within this and the companion document "the Missing Middle: Our Voices" Report, is both compelling and confronting.

Some respondents spoke of a broken system and how that system has broken them. Many talked about the GP as being their main support, how they want affordable choices and better communication and collaboration between practitioners and providers. Disengagement meant for some that the service didn't meet their needs or was not available, resulting in support being provided from their informal networks. Others talked about disengagement followed by deterioration in mental health resulting in a crisis, isolation, a decline in community participation and employment, and greater dependency on families and carers.

Others spoke of a system where they are listened to, are involved in decision-making, where practitioners are neither judgmental nor stigmatising toward them and they are receiving care for the time they need it. All crucial elements of person-centred recovery.

Our desire is to bring the perspectives, experience and needs of both consumers, families and carers, which must be recognised and acknowledged, into the forefront of policy and reform processes of service planning, design, implementation, and evaluation.

This is the full research report and when you read through it, please recognise that every statistic has a face behind it. We urge the reading of 'Our Voices' Report which faithfully reports the joint experiences of consumers, families and carers in a way that cannot be ignored.

We commend these Reports to you.

Janne McMahon

Janne McMahon OAM
Founder and Executive Director

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1. Executive Summary

Lived Experience Australia (LEA) is the representative organisation for Australian mental health consumers, families and carers and was previously known as the Private Mental Health Consumer Carer Network (Australia) Ltd, formed in 2002. LEA is the only consumer and carer advocacy organisation with a focus on services provided within private sector settings as well as having over 2,000 individual consumer and carer members and a social media following of over 800.

Our core business is to advocate for systemic change, empowerment of consumers and carers in their own care, promoting engagement and inclusion of consumers and carers within system reform processes, design, planning, implementation, and evaluation. Most importantly, our core business is advocating for consumer choice and family and carer inclusion. This encompasses advocacy for consumers and carers across the healthcare system, not only within the private sector. This is because we know that people's experiences of help-seeking happen at many points and parts of the overall system (regardless of whether they have private health insurance or not) and can include primary care/ General Practice, hospital emergency departments, community managed organisations, psychological therapy services, and community mental health services.

This report provides a national collective voice of people with a lived experience seeking input from those who either have sought or accessed mental health services, and their families and carers. It provides a detailed account of their experiences of seeking, receiving and (in many cases) disengaging from support from mental health professionals and services across different service types.

1.1 Background:

The Productivity Commission and others have adopted the term the 'missing middle' to describe, "people who need intensive community support to recover and go on with their lives...they fall between inpatient hospital services, and services for people with mild to moderate mental health problems".¹ Lived Experience Australia has undertaken a national survey to better understand the reasons why people slip through the gaps (i.e. don't engage or don't get the mental health care they need), and to have the first robust data from an Australian lived experience perspective. We wanted to understand why some consumers continue receiving support from a health

professional or service to improve their mental health (engage) while others cease their involvement with services (disengage) whether by choice or not.

A survey was offered by LEA to consumers, families and carers across Australia to provide feedback on their experiences of seeking and accessing mental health services. The survey was distributed by LEA to our members (1,113 with current email addresses) those that had previously engaged with LEA in other activities, and by request for further distribution, through LEA's consumer and carer organisational networks. In total, and despite being open for only 3 weeks, 535 commenced the survey with approximately 60% completing all questions. This gives us a sense of the high-level enthusiasm of consumers and carers in wanting to provide feedback regarding access to mental health services.

The survey consisted of 42 questions for consumers and 39 questions for carers and family members (see Appendix 1). The survey took 30-60 minutes (and more) to complete, dependent on people's willingness to provide further comments across the survey questions. Many people provided extensive comments about their experiences.

A large proportion of the survey focussed on collecting qualitative data to better understand the experiences of consumers, families and carers. The qualitative data was analysed using thematic analysis and reviewed by two separate researchers to ensure findings were transparent and robust. The range of consumer, family and carer qualitative responses to the survey have been captured in an accompanying report titled "Missing Middle – Our Voices".

This report provides an overview of the responses and separate sections highlighting feedback from both consumers and families/carers.

1.2 Key Findings:

Overwhelmingly, consumers, families and carers reported that they want affordable mental health services and a choice of providers. They want mental health professionals who they can trust, who will listen to them, are empathetic, involve them in decision-making, and who are not judgmental or stigmatising towards them.

¹ Swerissen H. & Duckett S. (2020) A Primary Health Network redesign to address the 'missing middle' in mental health. <https://www.croakey.org/a-phn-redesign-to-address-the-missing-middle-in-mental-health/#:~:text=The%20missing%20middle,to%20moderate%20mental%20health%20problems>

They want staff who are trained in trauma-informed and recovery-oriented care that will support their recovery and not cause further harm or trauma.

They want to be able to access support for the length of time it is needed and for it to be available when it's needed most to prevent deterioration of their mental health resulting in crisis.

They want continuity and consistency in providers and for mental health professionals involved in their care to communicate better with each other so that they do not have to tell their story over and over again.

They want services to follow up if they disengage and find out why they disengaged. They want access to people with a lived experience (e.g. peer workers) who can empathise with them, help them navigate the mental health system (including eligibility requirements), and support them on an ongoing basis.

The results from this survey tell us that people 'fall through the gaps' when these needs cannot be met. Key findings are outlined below:

Consumers and carers reported using their GP as their primary mental health support due to trust, value of interpersonal supports (listening, in control, collaboration, safety, not being judged), affordability and lack of alternative options.

Both the consumer and carer groups identified General Practitioners (GPs) as the most frequently used primary mental health support followed by a psychologist, counsellor or therapist, or public mental health services (MHS)/hospitals/ community teams.

For those consumers and carers who indicated that GPs were the main support they had accessed in the past 5 years, the results suggest that people are more likely to value and trust the interpersonal support (trust, listening, in control, collaboration, safety, not feeling judged/stigmatised, etc) they receive from their GP as the main reason why they engage with GPs, compared with public MHS where they consistently rated lower across these questions. In stark contrast to the above reasons, comments by the those who said they mainly engage with public MHS overwhelming stated that they had no choice as the main reason. Other reasons included the 'devil you know', they cannot afford private support alternatives, and they were told to go there for help. Of note, no positive comments were made.

Over half of both consumer and carer respondents identified that not being able to access mental health services when needed contributed to the consumer going into crisis. 40% of both consumer and carer respondents could not access mental health services at the point they needed it within a reasonable timeframe. Difficulties accessing mental health support was identified as the main reason for deterioration in mental health and wellbeing leading to crisis. Half of consumers who accessed an emergency department in crisis and were discharged without being admitted, did not have follow up or receive referrals after discharge.

Carers also identified the importance of having a trusted relationship with the provider, being heard and validated, convenience, accessibility, and having a lack of alternative choice of providers and therefore engaging with services that were affordable, even if the quality was compromised. Carers also noted the positive influence of having access to NDIS support.

Over half of consumers and carers are not able to access mental health support for themselves or the person they care for when they need it resulting in deterioration of their mental health and wellbeing resulting in crisis. Other factors contributing to deterioration in mental health resulting in crisis rated by over a third of both consumers and carers included social issues, not being connected to services, regular health professional not being available or not having a regular health professional to contact. Carers also commented on waiting times and unhelpful services contributing to deterioration in mental health of the person they support.

When in a crisis, half of consumers reported accessing an emergency department and two thirds of carers reported the person they care for accessed an emergency department. For those who were discharged from hospital without being admitted to a hospital ward, almost half of consumers had no follow up and 42% had no referral, whereas 18% of carers said the person they care for had no follow up with some also commenting that following discharge the person they care for attempted or committed suicide.

Consumers are not receiving mental health support for the length of time it is required often due to affordability or difficulties navigating the mental health system and eligibility requirements.

A large proportion of consumers are not getting mental health support for the length of time it is needed, with 40% of consumers and 53% of carers stating that support was not provided for long enough. The main issues regarding length of support included issues navigating the mental health system, eligibility for support, affordability, and service model constraints. For those who have not been supported for the time required, over half were not intending to find alternative support for their mental health care.

For almost half of the consumer respondents, they decided to end the support because the service was not meeting their needs, or they were unable to afford the support. When the service ended support, it was often due to no longer meeting eligibility criteria, or subsidised sessions running out (i.e. mental health plan). Carers reported that either the person or the service simply gave up, care and support stagnated, the service wasn't helping and was sometimes making the person's condition worse, or they now believed that NDIS would better meet the person's needs.

Lack of communication and collaboration between health professionals results in people falling through the gaps, having to re-tell their story and a lack of consistency in their mental health support.

Over half of both consumer and carer groups identified that, in their experience, there had been no communication or collaboration between health professionals involved in their care. Over 30% of both consumers and carers said they fell through the gaps, had to re-tell their story each time, had no consistency in health professionals or contacts, and had a lack of referrals for follow-up support.

Disengagement from mental health services is a significant issue and often occurs due to affordability, poor quality service, not feeling safe, lack of clear goals/progress, long waiting lists, not being listened to or involved in decision making and lack of continuity or follow up. The impact of disengagement is deterioration in mental health which can result in crisis, self-medicating, isolation, homelessness, and suicide.

Almost all consumers and carers said that disengagement from support was an issue and that disengagement often occurred because of affordability or running out of subsidised sessions, poor service quality, lack of continuity or follow up, or lack of choice with carers also identifying a lack of meaningful links to community beyond clinical support as key factors.

The reasons why people disengage were consistent across both the consumer and carer groups, with the key themes being a lack of service follow-up, not feeling safe, the service not meeting their needs, poor quality care, not having clear goals or progressing, not being listened to, collaborated with or involved in decision making, long wait-times and affordability of services. Consumers also highlighted issues with feeling judged and stigmatised, and carers highlighted the trauma of having to repeat the consumer's story to multiple providers.

The impact of disengagement is significant, with both consumers and carers identifying deterioration of mental health often resulting in crisis, self-medicating, isolation, homelessness and impacts on family, friends or employment being the result. Consumers also identified impacts including suicidal thinking, self-harm or risky behaviours when disengaged from support. Carers identified that responsibility falls to the families/carers to support the person when they are not engaged in mental health support.

When consumers disengage from a service, the most likely service they will go to in future for their mental health needs is a GP, psychologist, or psychiatrist.

Strategies suggested by both consumer and carer respondents to support engagement or re-engagement with mental health services included better quality providers, staff training, availability of peer workers with lived experience, affordability, persistent follow up, consistency, continuity and coordinated support.

A large proportion of consumers and carers provided suggestions to support ongoing engagement or re-engagement with mental health services. Consistent themes from both consumers and carers including better quality service providers, better trained staff, having peer workers available, consistent, and coordinated support, accessibility and availability of services, more persistent follow up from the service and being listened to. Consumers also commented on affordability of the services, collaboration, and communication between health professionals, and being involved in decisions about their care. Carers added further comments regarding the need for health professionals to have more empathy, involving families better, and providing more holistic care and systems-level consistency and coordination.

2. Survey Results

2.1 Demographics:

Summary:

From the 535 participants entering the survey, three quarters were consumers 75.5% (n=404) and one quarter were carers/family members 24.5% (n=131). Consumers, families/carers were redirected to separate sections of the survey. Specific demographics for consumer and carer/family member responses is shown in more detail below.

All states were represented in responses with a good range across states and territories, larger proportions of respondents were received from the larger states. There was also representation across all area types with 62.5% of respondents being from a capital city (n=326), 32% from a regional centre (n=168) and 5.5% from a remote town (n=28).

It was predominantly females completing the survey from both the consumer and carer groups with 82% being female, 15.5% male and 2.5% other.

Survey respondents varied in age, with most consumers and carers (n=490) being between 20-69 years of age.

There were 2.5% of respondents identifying as Aboriginal or Torres Strait Islander (n=13) and 17.5% who were not born in Australia (n=95), with most frequent country of birth identified as the UK (n=44), and New Zealand (n=17).

All responses:

This section provides an overview of all respondents participating in the survey. From the 535 participants entering the survey, 404 (75.5%) were consumers, and 131 (24.5%) were carers/family members.

Geographic Location:

All states were represented in responses with a good range across states and territories, most coming from the larger states (Figure 1) including:

- 25% from Victoria (n=132)
- 19% from Queensland (n=101)
- 17% from Western Australia (n=90)
- 17% from South Australia (n=89)

- 16% from New South Wales (n=86)
- 3% from Tasmania (n=16)
- 2% from ACT (n=10)
- 1% from Northern Territory (n=5)

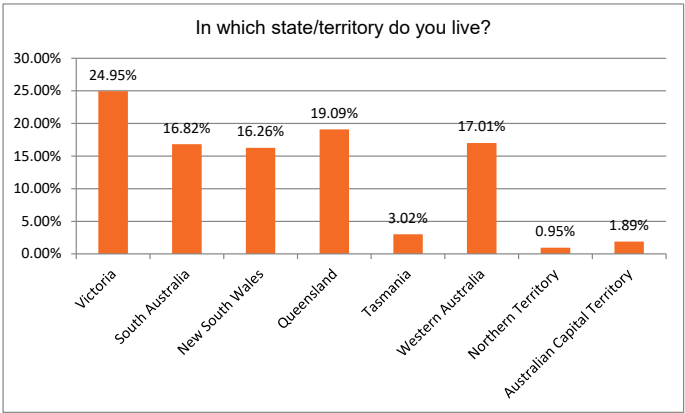


Figure 1: Summary of respondents – Geographic Location

There was also representation across all area types with 62.5% of respondents being from a Capital City (n=326), 32% from a Regional Centre (n=168) and 5.5% from a remote town (n=28).

Gender:

There were predominantly females responding to the survey who represented 82% of respondents (n=431), and 15.5% male (n=83) and 2.5% other (n=13).

Age Range:

Survey respondents varied in age, with most (n=490) being between 20-69 years of age (Figure 2 and Table 1).

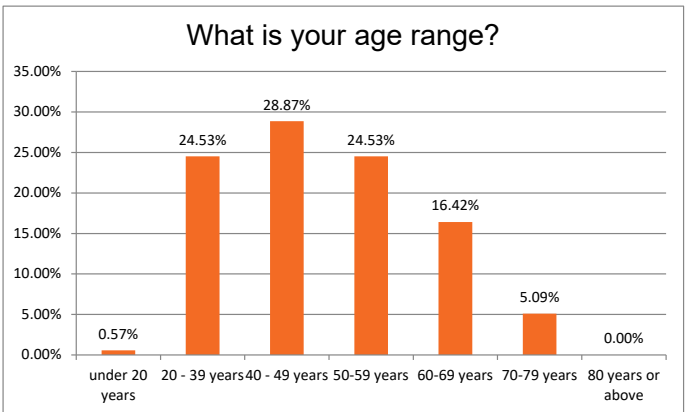


Figure 2: All Responses- Age Range

Table 1: All Responses- Age Range

Answer Choices	Responses	
under 20 years	0.57%	3
20- 39 years	24.53%	130
40- 49 years	28.87%	153
50-59 years	24.53%	130
60-69 years	16.42%	87
70-79 years	5.09%	27
80 years or above	0.00%	0

Cultural Background

Most respondents (95%, n=503) did not identify as being of Aboriginal or Torres Strait Islander decent, with 2.5% responding yes (n=13) and 2% who preferred not to say (n=12).

95 respondents were not born in Australia, with a wide range of responses regarding country of birth (Table 2).

Table 2: Country of Birth

Country of Birth	Number
United Kingdom	44
New Zealand	17
Canada	3
Germany	3
Singapore	3
United States of America	3
Egypt	2
India	2
Italy	2
Malaysia	2
Fiji Islands	1
Holland	1
Hungary	1
Indonesia	1
Japan	1
Romania	1
South Africa	1
The Netherlands	1
Uganda	1
Venezuela	1
Wales	1
Zimbabwe	1
Total	93

Seven respondents (1%) speak languages other than English at home which included Auslan, Spanish, Dutch, Hungarian, Japanese, and Turkish.

Consumer Responses:

From the 431 consumers who completed this section of the survey, almost all respondents provided demographic details including geographic location, gender, age, cultural background, and languages spoken at home.

Geographic Location

Consumers were represented across all states and territories (Figure 3) with a larger number of responses from the larger states (Figure 3):

- Victoria 27.5% (n=110)
- Queensland 19.3% (n=77)
- New South Wales 15.8% (n=63)
- Western Australia 16.3% (n=65)
- South Australia 14.79% (n=59)
- Tasmania 3.26% (n=13)
- Australian Capital Territory 2% (n=8)
- Northern Territory 1% (n=4)

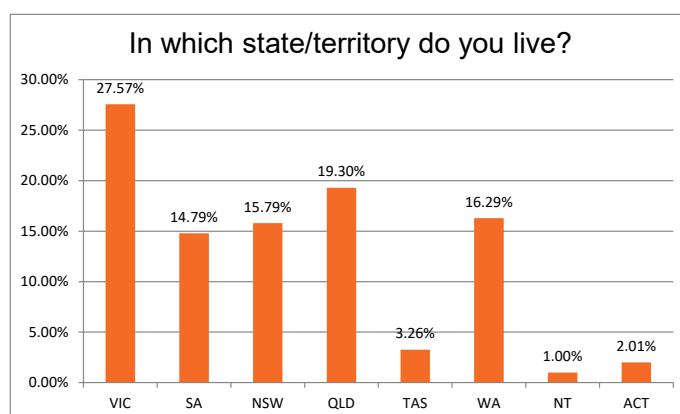


Figure 3: Consumers- Geographic Location

There was also a range of responses across geographic location types with 63% located in a capital city (n=251), 31% in a regional centre (n=123) and 5% from remote towns (n=20).

Gender:

A large proportion of consumers completing the survey were female 79% (n=317), with 18% (n=73) male and 2% (n=9) other also responding.

Age Range:

There was a varied age range of consumers responding to the survey, with over 95% (n=381) being between 20-69 years (Figure 4, Table 3).

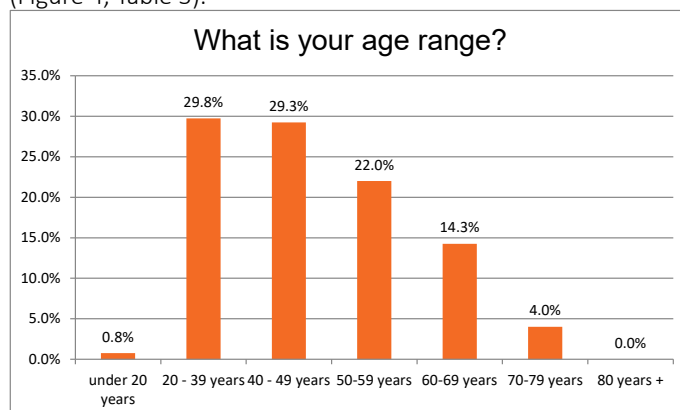


Figure 4: Consumers - Age Range

Table 3: Consumers – Age Range

Age range	Responses	
under 20 years	0.8%	3
20- 39 years	29.8%	119
40- 49 years	29.3%	117
50-59 years	22.0%	88
60-69 years	14.3%	57
70-79 years	4.0%	16
80 years +	0.0%	0

Cultural Background

Of the 400 consumers who completed this question, those who identified as being Aboriginal or Torres Strait Islander represented 3% (n=12). A total of 99% (n=397) speak English as their main language at home. There were 16.5% (n=66) who were not born in Australia; of these, approximately two-thirds were born in the UK or New Zealand, with respondents being from 20 different countries (Table 4).

Table 4: Consumers – Cultural Background

Country of Birth	Number
Egypt	2
USA	1
Canada	2
Fiji Islands	1
Germany	1
Holland	1
Hungary	1
India	1
Venezuela	1
Italy	1
Japan	1
Malaysia	2
New Zealand	11
Romania	1
Singapore	3
South Africa	1
UK	32
Indonesia	1
Zimbabwe	1
Israel	1

Carer Responses:

A total of 131 carers provided demographic details; these were sought by geographic location, gender, age, cultural background, and languages spoken at home.

Geographic Location

Carers were represented across all states and territories with response rates per location being larger in the larger states (Figure 5).

- Victoria 17% (n=22)
- South Australia 23% (n=30)
- New South Wales 18% (n=23)
- Queensland 18.5% (n=24)
- Tasmania 2% (n=3)
- Western Australia 19% (n=25)
- Northern Territory 1% (n=1)
- ACT 1.5% (n=2)

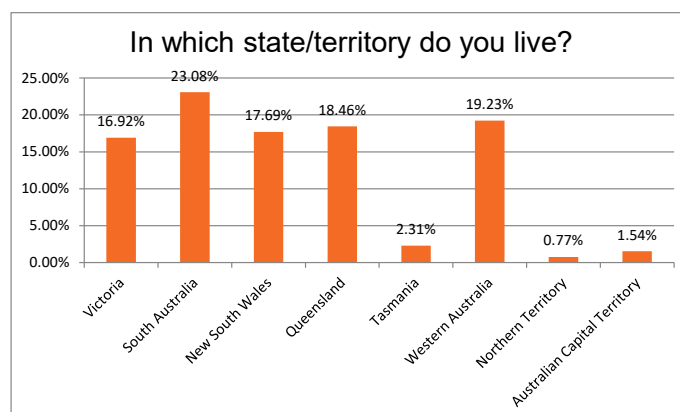


Figure 5: Carers - Geographic Location

Of the 130 family/carers respondents who identified their location, 58.6% (n=75) were located in capital cities, with 35.15% (n=45) in regional centres/rural and 6.25% (n=8) in remote towns.

Gender:

Most family/carers respondents identified as female (89.06%, n=114), with remaining respondents identifying as male (7.81%, n=10) or other (3.13%, n=4).

Age Range:

There was a varied age range of carers responding to the survey, with the majority being between 20-69 years (Figure 6, Table 5).

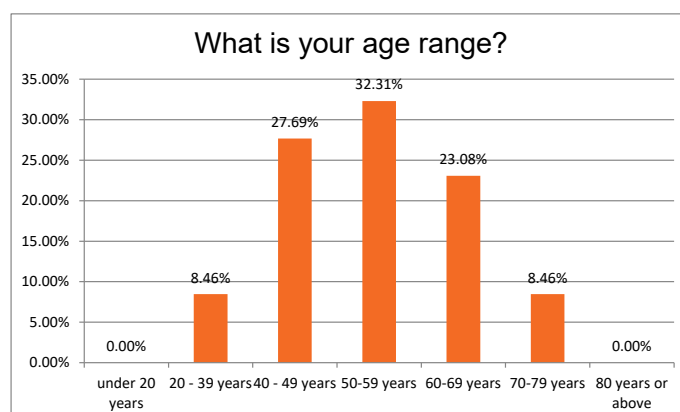


Figure 5: Carers - Age Range

Table 5: Carers Age Range

Answer choices	Responses	
under 20 years	0.00%	0
20- 39 years	8.46%	11
40- 49 years	27.69%	36
50-59 years	32.31%	42
60-69 years	23.08%	30
70-79 years	8.46%	11
80 years or above	0.00%	0

Cultural Background

Of the 128 carers who completed the question, those who identified as being Aboriginal or Torres Strait Islander represented 1% (n=1), with 4.69% (n=4) respondents preferring not to say and 94.53% (n=121) not identifying as being Aboriginal or Torres Strait Islander.

Most respondents (97.62%, n=123) spoke predominantly English at home. Of those who speak a language other than English, languages included Spanish, Dutch and Turkish, with one of these respondents also speaking Auslan.

There were 29 respondents born overseas (Table 6).

Table 6: Carers – Cultural Background

Country of Birth	Number
New Zealand	6
UK	5
England	3
Germany	2
Scotland	2
USA	2
Canada	1
Egypt	1
Great Britain	1
India	1
Ireland	1
Italy	1
Netherlands	2
Uganda	1



2.2 Main Mental Health Services Accessed:

Summary:

Both consumer and carer respondents identified accessing General Practitioners (GPs) as their primary source of mental health support over the past 5 years, with a psychologist, counsellor or therapist, or public mental health services/hospitals/community teams also rated highly.

Consumers identified that the reasons for using their primary mental health support included trust, safety, control in making decisions, feeling included and not judged, having a lack of alternative options, affordability with other options being too expensive and the quality of the relationship. Carers highlighted the importance of having a trusted relationship with the provider, being heard and validated, convenience and accessibility as the key themes. A lack of alternative and therefore engaging with services that were affordable, even if the quality was compromised was also identified by many carers, and the positive influence of having access to NDIS support was noted.

Where GPs were primarily used over the past 5 years as the key mental health support, consumers and carers indicated that they are more likely to value and trust the interpersonal support (trust, listening, in control, collaboration, safety, not feeling judged/stigmatised, etc) they receive from their GP, compared with public mental health services where they consistently rated lower across these questions. Of interest, ratings for choice, consistency of worker, and service coordination were similar across views about GPs and Mental Health Services (MHS).

In stark contrast to the above reasons, comments by the 27 respondents who said they mainly engage with public MHS overwhelming stated that they had no choice to explain the main reason why they engaged with public MHS. Other reasons included: The 'devil you know', they cannot afford private support alternatives, and they were told to go there for help. Of note, no positive comments were made.

Comments provided by consumers highlighted their typical experiences in accessing mental health support which provided a more nuanced understanding of the reasons for their choice of responses to the questions. These included receiving quality support, often at significant financial cost to secure a quality service. However, several respondents also noted a lack of actual choice, and tolerating substandard support and service because of this, or long wait-times, or because it enabled access to other needed services and supports.

Of the 67 consumers who use digital resources or apps, the main reason for using these included the comparative cost of face-to-face services (21%, n=53), convenience (19%, n=48), wanting to try something new (14%, n=36), it was recommended by my health professional (13%, n=34) and dissatisfaction with other services (12%, n=30). Furthermore, consumers who accessed online resources, also accessed medication (35%, n=88) and were also accessing support from a mental health professional (34%, n=84). Consumers who commenced an online course for support but disengaged, identified the main reasons being not ready to commit (7%, n=17), and that it was no longer relevant (7%, n=17). Main comments included lack of motivation, not knowing online courses were available and concerns about privacy.

Consumer Responses:

When asked what services, health professionals and supports they have access for their mental health over the past 5 years, a majority of consumers identified GPs (68%, n=195) and psychologist, counsellor, or therapist (63%, n=180) as their main mental health support (Figure 7). Other support services identified, in order of highest frequency included:

- GPs 68% (n=195)
- Psychologist, counsellor or therapist 63% (n=180)
- Public mental health services/hospitals/community teams 35.79% (n=102)
- Peer support (organised or unorganised) 30.18% (n=86)
- Private mental health services/hospitals 25.61% (n=73)
- Online or digital resources or Apps 23.51% (n=67)
- Only used a Private Psychiatrist 19.65% (n=56)
- Telehealth 18.25% (n=52)
- Other (please specify) 9.47% (n=27)
- Veteran supports 1.05% (n=3)

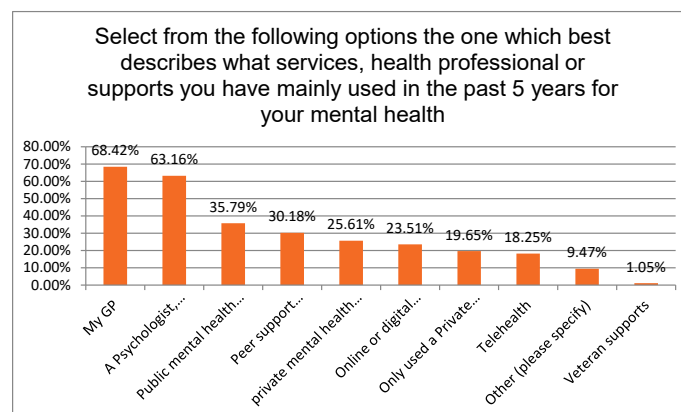


Figure 7: Consumers- Services Accessed

When asked the main reason why they use this as their main mental health support, most identified that it was due to trust, safety, control in making decisions, and feeling included and not judged (Figure 8). The top reasons listed by over 80% (n=222) of respondents as a contributing or major contributing reason (in order of highest rated) were:

- I trust them 85.45% (n=235)
- They listen to me 85.09% (n=234)
- I feel I have some say or control in making decisions 84.98% (n=232)

- I feel safe there 84.56% (n=230)
- The service meets my needs 82.25% (n=227)
- I don't feel judged/stigmatised by them 81.45% (n=224)
- They include/collaborate with me 80.73% (n=222)

- Other contributing reasons of note, listed by highest rating included:
- I don't have to wait too long to see someone 70.22% (n=191)
 - They don't make me repeat my story too much 68.38% (n=186)
 - I can afford to pay for this service 67.77% (n=185)
 - I have a consistent worker 64.68% (n=174)
 - Limited options/choice of service providers in my area 56.13% (n=151)
 - They seem to have a clear plan/goals 54.04% (n=147)
 - They respect my privacy if I don't want to include my family 49.63% (n=135)
 - They are organised and coordinate the support services I need 48.71% (n=132)
 - I am able to see a worker whose gender is of my choosing 36.3% (n=98)
 - They include my family/carer 20.88% (n=57)

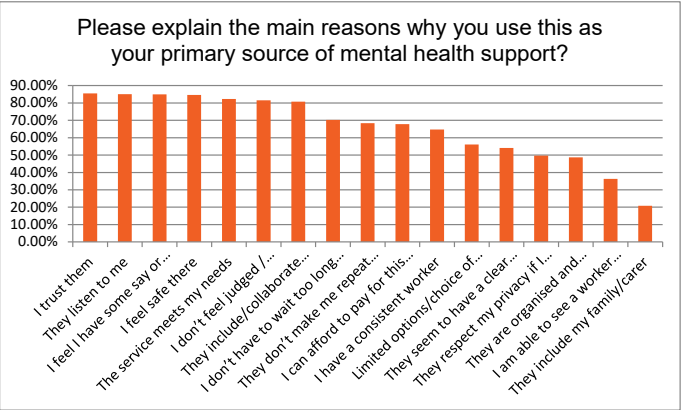


Figure 8: Consumers – reason for using primary source of mental health support

Some consumers identified accessing support from church support/spiritual coaching, private psychiatrists, holistic health practitioners, mental health nurses, and employee assistance programs. Some consumers also identified other contributing factors such as lack of alternative choices (n=20), affordability of selected option or other options being too expensive (n=15), and the quality of the relationship (n=9).

For those consumers and carers who indicated that GPs were the main support they had accessed in the past 5 years, the results shown in Table 7 suggest that people are more likely to value and trust the interpersonal support (trust, listening, in control, collaboration, safety, not feeling judged/stigmatised, etc) they receive from their GP as the main reason why they engage with GPs, compared with MHS where they consistently rated lower across these questions. Of interest, ratings for choice, consistency of worker, and service coordination were similar across views about GPs and MHS.

Table 7: Consumers - Services, Health Professional or Supports Consumers have mainly used in the past 5 years – Comparing Responses for GP and MHS

	GP CONSUMERS n=191 n=191	MHS CONSUMERS n=191 n=191	GP CONSUMERS n=191 n=191	MHS CONSUMERS n=191 n=191	GP CONSUMERS n=191 n=191	MHS CONSUMERS n=191 n=191	GP CONSUMERS n=191 n=191	MHS CONSUMERS n=191 n=191	GP CONSUMERS n=191 n=191	MHS CONSUMERS n=191 n=191
I don't have to wait too long to see someone	70.22%	70.22%	70.22%	70.22%	70.22%	70.22%	70.22%	70.22%	70.22%	70.22%
The service meets my needs	82.25%	82.25%	82.25%	82.25%	82.25%	82.25%	82.25%	82.25%	82.25%	82.25%
I don't feel judged/stigmatised by them	81.45%	81.45%	81.45%	81.45%	81.45%	81.45%	81.45%	81.45%	81.45%	81.45%
They include/collaborate with me	80.73%	80.73%	80.73%	80.73%	80.73%	80.73%	80.73%	80.73%	80.73%	80.73%
I don't have to wait too long to see someone	70.22%	70.22%	70.22%	70.22%	70.22%	70.22%	70.22%	70.22%	70.22%	70.22%
They don't make me repeat my story too much	68.38%	68.38%	68.38%	68.38%	68.38%	68.38%	68.38%	68.38%	68.38%	68.38%
I can afford to pay for this service	67.77%	67.77%	67.77%	67.77%	67.77%	67.77%	67.77%	67.77%	67.77%	67.77%
I have a consistent worker	64.68%	64.68%	64.68%	64.68%	64.68%	64.68%	64.68%	64.68%	64.68%	64.68%
Limited options/choice of service providers in my area	56.13%	56.13%	56.13%	56.13%	56.13%	56.13%	56.13%	56.13%	56.13%	56.13%
They seem to have a clear plan/goals	54.04%	54.04%	54.04%	54.04%	54.04%	54.04%	54.04%	54.04%	54.04%	54.04%
They respect my privacy if I don't want to include my family	49.63%	49.63%	49.63%	49.63%	49.63%	49.63%	49.63%	49.63%	49.63%	49.63%
They are organised and coordinate the support services I need	48.71%	48.71%	48.71%	48.71%	48.71%	48.71%	48.71%	48.71%	48.71%	48.71%
I am able to see a worker whose gender is of my choosing	36.3%	36.3%	36.3%	36.3%	36.3%	36.3%	36.3%	36.3%	36.3%	36.3%
They include my family/carer	20.88%	20.88%	20.88%	20.88%	20.88%	20.88%	20.88%	20.88%	20.88%	20.88%

Fifty respondents provided further comments on why they use GPs as their main provider. Their comments covered a range of reasons with affordability compared to other mental health services such as psychology and private psychiatry being a prominent reason. Other reasons included:

- They show respect
- They listen
- The person had greater control of decisions
- They bulk-bill
- Consistency and relationship
- Fear of Mental Health Services
- They engage in 'How-to' conversations and self-care management
- No choice in regional areas
- They also look after physical health

In stark contrast to the above reasons, comments by the 27 people who said they mainly engage with public MHS overwhelming stated that they had no choice to explain the main reason why they engaged. Other reasons included: The 'devil you know', they can't afford private support alternatives, and they were told to go there for help. Of note, no positive comments were made.

Carer Responses:

When asked what services, health professionals and supports the person they care for has accessed for their mental health over the past 5 years, carers who responded identified public mental health services/hospitals/community teams 61.5% (n=59) and GPs 59% (n=57) as the main mental health support

(Figure 9, Table 8). Some carers also identified Headspace and Support Workers.

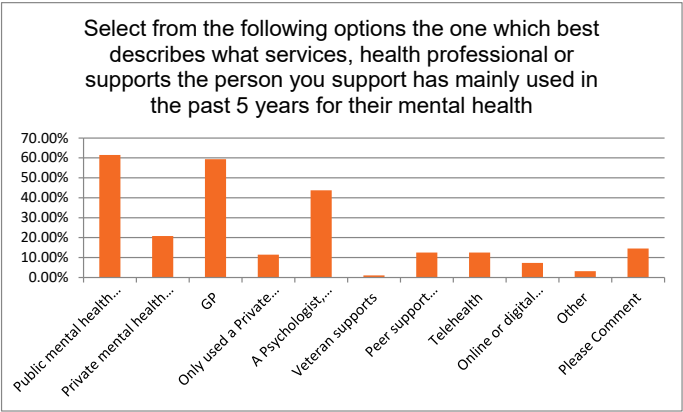


Figure 9: Carers – Services Accessed

Table 8: Carers – Services Accessed

Answer Choices	Responses	
Public mental health services/ hospitals/community teams	61.46%	59
Private mental health services/ hospitals	20.83%	20
GP	59.38%	57
Only used a Private Psychiatrist	11.46%	11
A Psychologist, counsellor/therapist	43.75%	42
Veteran supports	1.04%	1
Peer support (organised or unorganised)	12.50%	12
Telehealth	12.50%	12
Online or digital resources or Apps	7.29%	7
Other	3.13%	3

When asked the main reason why the person they care for uses the above as their primary mental health support, there was a range of responses with the most frequently selected being affordability (40.86%, n=38), limited options/choice (36.56%, n=34), the service meets their needs (34.41%, n=32), and they listen to them (34.41%, n=32) (Figure 10, Table 9).

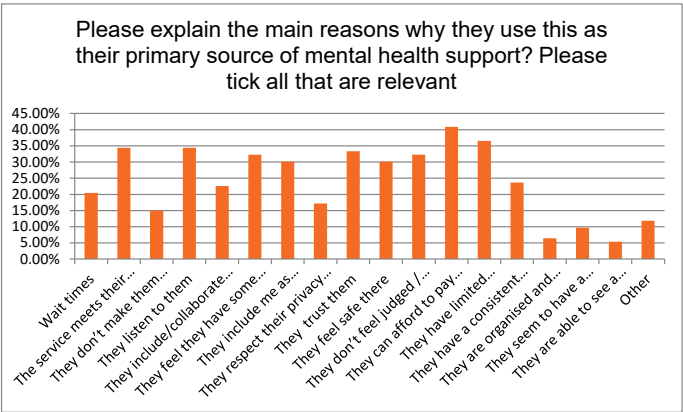


Figure 10: Carers – reason for using primary source of mental health support

Table 9: Carers - Reasons for using primary mental health support

Answer Choices	Responses	
They can afford to pay for this service	40.86%	38
They have limited options/choice of service providers in their area	36.56%	34
The service meets their needs	34.41%	32
They listen to them	34.41%	32
They trust them	33.33%	31
They feel they have some say or control in making decisions	32.26%	30
They don't feel judged / stigmatised	32.26%	30
They include me as family/carer	30.11%	28
They feel safe there	30.11%	28
They have a consistent worker	23.66%	22
They include/collaborate with them	22.58%	21
Wait times	20.43%	19
They respect their privacy if they don't want to include their family	17.20%	16
They don't make them repeat my story too much	15.05%	14
Other	11.83%	11
They seem to have a clear plan/goals	9.68%	9
They are organised and coordinate the support services they need	6.45%	6
They are able to see a worker whose gender is of their choosing	5.38%	5

I don't have a lot of choice. The services I use are pretty poor and extremely expensive which means I can only rarely use them and a lot of the time I have no support.

- Consumer Comment

2.3 Accessibility of Services:

Summary:

Over 40% of consumers and over 40% of carers identified not being able to access mental health services at the point that they realised it was needed, within a reasonable timeframe.

Most respondents provided further comment regarding this question, demonstrating the strong views of both consumers and carers regarding access to support and waiting times for appropriate services.

Consumers commented on the long wait times, difficulties in finding the 'right' or 'appropriate' mental health service. For many, although they were able to access some form of mental health service, it either took a long time to find a service that met their needs, or they were still seeking appropriate support. The complexities in accessing support during COVID-19 were also identified by several consumers. Carers explained their experience and its impact, and perceived reasons for problems with access. This included lack of available services, lack of follow up once discharged from hospitals or EDs, systems focused on flow or their own business or service model and 'hand-balling' responsibility to other providers, cost, stigma and dismissiveness by services, and the long wait times for follow-up with community supports were dominant themes.

Consumer Responses:

Consumers were asked if they were able to access mental health services at the point that they realised they needed it within a reasonable timeframe. Responses were split with 59% (n=164) indicating they were able to and 41% (n=115) indicating that they were not able to (Figure 11).

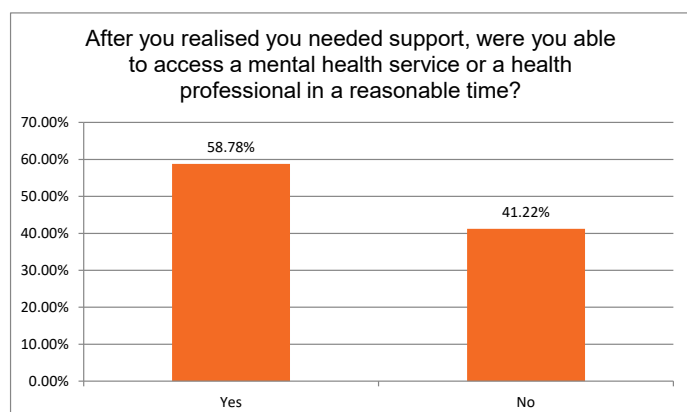


Figure 11: Consumers – Accessibility of services

Of note, 171 consumers provided further comment to this question, demonstrating the strong views of consumers regarding access and wait times for appropriate services. From those commenting, many talked about the long wait times, with 19 highlighting a wait time of 1-3 months, 14 waited 3-6 months and 18 waiting more than 6 months, and a few of these were still waiting for appropriate support services. Several

consumers highlighted the difficulties in finding the 'right' or 'appropriate' mental health services. For those consumers, although they were able to access some form of mental health services, it either took a long time to find a service that met their needs, or they were still seeking appropriate support; some received services that didn't meet their needs and some received no service at all. The complexities in accessing support during COVID were identified by several consumers.

Some of the typical comments from respondents demonstrated the above concerns about wait times, their persistence and patience in trying to find services to meeting their needs, and to navigate often complex systems and information in the process of help-seeking.

Carer Responses:

Of the 94 family/carers respondents to this question, almost half (46.81%, n=44) said that the person could not access a mental health service or health professional in a reasonable time once they realised that they needed support (Figure 12).

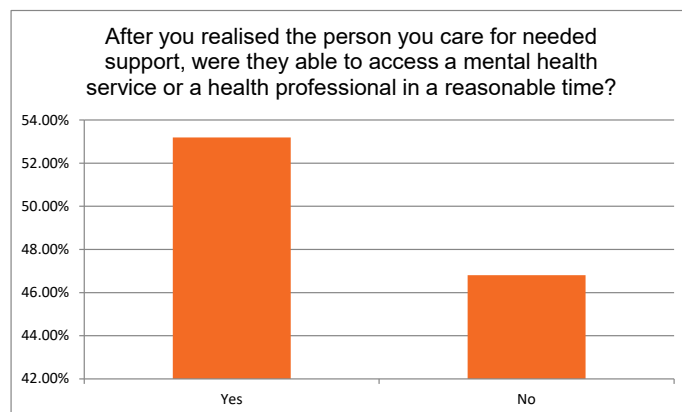


Figure 12: Carers – Accessibility of services

I have spent so many months of my life on waiting lists that it's become almost funny. Luckily I am receiving support from multiple services, so when I am on the waiting list for one I am usually seeing at least somebody, but I have struggled so much to receive appropriate wraparound support due to wait times.

- Consumer Comment

2.4 Qualities of the Service and Health Professional:

Summary:

More than half of consumer and carer respondents identified that there were particular qualities of a service that made them feel more comfortable and supported engagement. Most consumers provided further comment with the key themes being that the service was accepting, non-judgemental, listened, friendly staff and health professionals, flexible options such as availability and range of providers, affordability, specialised support, consistency in service/health professional, feeling safe, having staff with a lived experience, long term relationships, trauma informed care and choice. Carer comments were consistent with these, emphasising the importance of a familiar and safe environment, feeling respected, providing quality services in which there is flexibility, consistency and continuity of support, good communication with the consumer, the family and each other, and being empathetic and committed.

When asked if there were particular qualities of the health professional that helped them to engage, 77% (n=211) of consumers and 55% (n=51) of carers identified that there was. Consumers commented on the health professional's knowledge and experience, that they listen, are accepting and non-judgemental, having staff with a lived experience and that they have a say in their own treatment. Several consumers also commented on having a choice of gender of the health professional, having a relationship that was the right fit and knowledge of trauma informed care as important qualities. Carer responses were consistent with the above, identifying non-judgemental, commitment, being 'human', having staff with a lived experience and having a more holistic understanding of recovery as key qualities.

Consumers also identified the qualities that made them feel uncomfortable and not wanting to engage included the health professional having a lack of knowledge and/or experience, being unprofessional and being focussed on medication rather than therapy. Carers noted qualities that made them feel uncomfortable or the person they support not want to engage emphasising health professionals that showed disinterest, were judgemental, did not work in a trauma informed way, pushing their own agenda, coercive care (Community Treatment Orders) and long wait-times that led to the person not wanting to engage or stay engaged.

Consumer Responses:

When asked if there were particular qualities of the service that made them feel more comfortable, 65% (n=179) of consumer respondents stated there were. 170 consumers provided further comment with a large number based on the following themes: the service was accepting and non-judgemental (n=17), friendly staff and health professionals (n=14), flexible support options such as availability and range of providers (n=13), cost (n=11), they listened to me (n=11) and being a specialised, consistent service or health professional (n=19). Other comments identified location, feeling safe, having staff with a lived experience, long term relationship, trauma informed care and choice as qualities that made them feel more comfortable.

When asked if there were particular qualities of the health professional that helped them to engage with the health professional, 77% (n=211) of respondents identified that there were. In response to this question, 182 people provided further comment, a large number commenting that what helped then was the health professional's knowledge and experience (n=40), that the health professional listened to them (n=39), that they were accepting and non-judgemental (n=37) and that they had a say in their own treatment (n=13). Other, less frequent comments included the gender of the health professional (having a choice in gender), the lived experience of the health professional, the relationship was the right fit, working at the person's pace and having knowledge of and provided trauma-informed care.

When asked if there were particular qualities about the health professional that made the respondent feel uncomfortable and not want to engage with them, 46% (n=124) of consumers identified there were. There were 128 consumers who provided further comment to this question which included not listening (n=33), being judgemental (n=28), lack of knowledge and/or experience (n=19), being unprofessional (n=17) and being focussed on medication rather than therapy (n=7).

Carer Responses:

When asked if there were particular qualities of the service that made the person they care for feel more comfortable, 94 family/carer provided a response with more than half (54.26%, n=51) saying that there were. Sixty-one (61) respondents provided additional comments, emphasising the importance of a familiar and safe environment, feeling respected, and providing quality services in which there is flexibility, consistency and continuity of support, and where staff communicate well with the person, the family and each other and are empathic and committed.

When asked if there were particular qualities of the health professional that helped the person they care for to engage with them, 93 family/carer responded with more than half (54.84%, n=51) saying there was, only 17.20% (n=16) saying there wasn't, and 27.96% (n=26) were unsure.

Fifty-one respondents provided additional comments, with being non-judgmental, committed, human, having a more holistic understanding of recovery, and having lived experience noted as dominant themes.

When asked if there were qualities of the health professional or service that made the person feel uncomfortable/not want to engage, 94 family/carers responded with well over half (59.57%, n=56) saying 'yes', 22.34% (n=21) said 'no', and 18.09% (n=17) were unsure. Fifty-three respondents provided additional comments, emphasising that health professionals showing disinterest, or being judgmental or not working in a trauma informed way, pursuing their own agenda, coercive care (Community Treatment Orders) and long wait-times for service led the person to not want to engage.

Their sense of humour, empathy, and their belief in my ability to recover plus they could give me a little push when needed. Really a range of things.

- Consumer Comment

2.5 Length of Support Provided:

Summary:

When asked if the health professional or service supported the consumer for the length of time they needed, 40% (n=110) of consumers and 52% (n=44) of carers stated no. For the consumers who were not supported for the length of time they needed, 44% (n=63) stated that they chose to end the support, 20% (n=29) identified that the service decided to end the support and 22% (n=31) identified 'other' for who made the decision to end support. In total, 64% (n=94) of consumers who did not receive the support for the time they needed, stated that they did intend to find alternative support for their mental health care, and 51% of carers said that the person they care for is not or will not be seeking alternative mental health support. Carers identified that the decision to end support was made by either the person (32.79%, n=20), the service (29.51%, n=18), or others either known or unknown to them.

When consumers chose to end the support, the most frequent reasons included the support was not meeting their needs or it was too expensive. When services ended support, consumers stated that the main reasons included running out of funded sessions (e.g. mental health care plan) or no longer being eligible for support.

Carers commented on a broad range of concerns and experiences which included problems navigating eligibility and service access and constraints of the service model itself. Some carers also noted that problems with the service, not understanding the needs of the person they are supporting, and in many cases that either the person they care for or the service simply giving up, care and support stagnating, the service not helping or now believing that NDIS would meet the persons needs.

Consumer Responses:

For those who were not supported for the length of time they needed, it was primarily the consumer who made the decision to end support (Figure 13, Table 11).

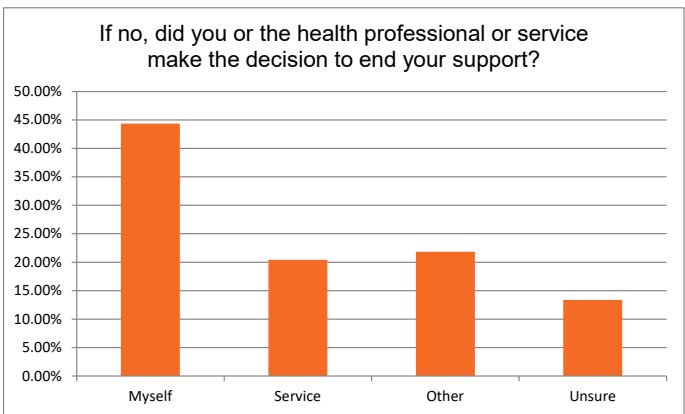


Figure 13: Consumers - Who made the decision to end support?

Table 11: Consumers - Who made the decision to end support?

Answer Choices	Responses	
Myself	44.37%	63
Service	20.42%	29
Other	21.83%	31
Unsure	13.38%	19

In total, 86 consumers provided further comment the decision to end support. The most frequent reasons why consumers chose to end the support was due to the support not meeting their needs or helping them (n=19) or being too expensive (n=10). The most frequent reasons why the service ended the support was due to running out of funded sessions e.g. mental health care plan (n=17) or was no longer eligible for support (n=3).

Carer Responses:

When asked if the person they care for was supported for the length of time they needed, 93 family/carers provided a response with more than half (52.69%, n=44) saying that the health professional or service did not help the person for the length of time that the family/carer felt they needed it. Fifty-two respondents provided additional comments, identifying a broad range of concerns and experiences. These included the problem of navigating eligibility and service access, and constraints of the service model itself.

Family/carers responded to the question when support was not provided for the length of time needed, who made the decision to end support, stating that the decision to end support was made by either the person (32.79%, n=20), the service (29.51%, n=18), or others either known or unknown to them. Thirty-six family/carer respondents provided additional comments which indicate that in many cases, either the person or the service simply gave up, care and support stagnated, the service wasn't helping or they now believed that NDIS would meet the person's needs. More than half of family/carer respondents (51.61%, n=32) who said support was not provided to the person for the length of time needed also said that they did not or are not intending to find alternative mental health support.

Mum gets discharged very quickly from services and she has never been linked with proper therapy for her problems. She just gets "managed" for a short period....and then quickly exited from the service. People don't try to come and see her at home and they never contact her family for input.

- Carer Comment

2.6 Disengagement from support:

Summary:

Both consumers and families/carers overwhelmingly agreed that disengagement (stopping) use of mental health services as an issue of concern with over 91% (n=329 total) of respondents rating 'yes'.

When asked why they rated in this way, consumers reported concerns relating to affordability or running out of subsidised sessions, needing better quality, experienced and knowledgeable providers, a lack of service/health professional continuity requiring some consumers to retell their stories frequently, having a lack of choice in providers, support being too short term or having waiting lists that are too long, or in some cases consumers felt better and didn't think they required any further support. Carers provided further comment to this question than almost any other question in the survey. Carers identified several reasons for their views, noting lack of a caring approach, affordability, service communication issues, long wait-times, lack of trust in services, lack of follow-up and service continuity, and lack of meaningful links to community supports beyond clinical care.

Consumers who disengaged from services noted that the reasons for disengagement included not receiving the right support, services not meeting their needs (wrong care), cost being prohibitive, having limited options or a choice of services, having a lack of plan/goals or it didn't seem to be going anywhere, and being treated poorly by the health professional. From a personal perspective, consumers noted disengagement because they were not listened to, they felt judged/stigmatised, were not included/collaborated with, did not have a say in decision making, not feeling safe, being forgotten about, having to repeat their story too much and choosing an alternative service.

Carer responses were consistent with those of consumers, identifying major contributors for disengagement as not receiving the type of support that the person needed, care that didn't seem to be going anywhere/lack of plans/goals, limited choice of service providers in their area, affordability, lack of follow up and the service not meeting their needs. From a personal perspective, carers rated the major contributors to disengagement as feeling judged/stigmatised; services not listening to them; they were forgotten about; and they didn't trust services. Carers also emphasised several interpersonal experiences that led to disengagement. These included a loss of confidence in the service's ability to help them, the trauma induced by the person they care for having to repeat their story, and a focus on medical treatments in the absence of other supports for broader recovery.

Both consumers and families/carers who did not continue with a health professional or service but may need support in the future, rated GPs, psychologists, and psychiatrists as the most likely services they would try to engage with. Of interest, the fourth most prevalent response in both the consumer and carer responses, was engagement with a peer worker.

Both consumers and family/carer respondents overwhelmingly rated the impact of disengagement from services including mental health relapsing or deteriorating further. Consumers responded from their experience of disengagement from mental health services often resulting in a suicide attempt, self harm or risky behaviour, being isolated, losing hope, impact on family, friends, employment and/or study with some finding alternative support options. Some consumers commented that disengagement often resulted in significant crisis and trauma, finding other ways to self-manage, not always successfully, on their own without support. Carers emphasised that their future experiences with services were tainted, more responsibility for support falling to the family (if present), and loneliness, social withdrawal and isolation in the community, and 'self-medication' of their needs become increasing concerns; with some eventually finding supports outside the system.

Consumer Responses:

Consumers were asked if disengagement (stopping) use of mental health services was an issue of concern for them; 91% (n=245) stated that it was. In response to this question, 199 consumers provided further comment. The most frequent comments related to affordability being an issue or running out of sessions in a mental health plan (n=55), the need for better quality, experienced and knowledgeable providers (n=43), lack of consistency in providers (n=11) which for some required retelling their stories too many times, lack of choice in providers (n=5), support being too short term (n=9) or having waiting lists that are too long (n=9), thinking that they are better and no longer require support (n=4), and three consumers identified 'aging out' of a youth service and not getting access to appropriate adult mental health supports.

The reasons which were identified as not being a contributing reason for disengagement included not requiring the full number of appointments as they felt better quickly (81%, n=161), requiring a referral but not receiving one (70%, n=142), being told that they didn't meet/no longer met the criteria of the service (58%, n=118), and worker changing frequency/no consistent worker (53%, n=108) (Figure 14, Table 12).

Bar chart showing the percentage of respondents who considered each reason as a major, somewhat, or not contributing reason for not using a service. The reasons are: 'Didn't need the full number...', 'A referral was required but I...', 'Told that I didn't meet/n...', 'Worker changed frequently...', 'Wait times were too long...', 'Other', 'Discharged from mental...', 'Limited options from intake...', 'Lack of plan/goals didn't...', 'Cost was prohibitive I...', 'The service didn't meet my...', and 'The service didn't offer me...'. The legend indicates: Major contributing reason (green), Somewhat contributing reason (blue), Not a contributing reason (yellow), and Unsure (light blue).

Reason	Major contributing reason (%)	Somewhat contributing reason (%)	Not a contributing reason (%)	Unsure (%)
Didn't need the full number...	5.00%	5.00%	85.00%	5.00%
A referral was required but I...	10.00%	10.00%	70.00%	10.00%
Told that I didn't meet/n...	20.00%	15.00%	55.00%	10.00%
Worker changed frequently...	15.00%	15.00%	50.00%	20.00%
Wait times were too long...	30.00%	15.00%	45.00%	10.00%
Other	10.00%	10.00%	40.00%	40.00%
Discharged from mental...	25.00%	15.00%	40.00%	20.00%
Limited options from intake...	20.00%	15.00%	35.00%	30.00%
Lack of plan/goals didn't...	30.00%	15.00%	30.00%	25.00%
Cost was prohibitive I...	35.00%	15.00%	25.00%	25.00%
The service didn't meet my...	40.00%	15.00%	20.00%	25.00%
The service didn't offer me...	40.00%	15.00%	20.00%	25.00%

Table 12: Consumers - Primary reason for disengagement

Contributing Factor	Major contributor	Somewhat contributor	Not a contributor	Unknown	Total				
The service didn't offer me the right type of support that I needed	47.84%	101	27.83%	58	23.11%	48	6.42%	3	212
The service didn't meet my needs (anything else)	45.75%	97	24.83%	52	20.60%	57	2.83%	6	212
Cost was prohibitive; I couldn't afford to pay for it	42.45%	90	19.34%	41	34.83%	73	5.77%	8	212
Limited options/choice of service providers in my area	35.82%	75	25.30%	53	30.36%	75	2.39%	5	209
Lack of plan/goals didn't seem to be progressing going anywhere	34.78%	72	25.12%	52	35.27%	73	6.83%	10	207
Discharged from mental health/professional mental health service with no follow up	34.13%	71	20.12%	42	42.73%	89	2.83%	6	208
Wait times were too long	27.54%	57	20.77%	43	48.31%	100	3.38%	7	207
Told that I didn't meet/longer met criteria of the service	23.78%	48	13.37%	27	58.42%	113	4.46%	0	202
Worker changed frequently/ no committed worker	21.95%	45	19.51%	40	52.68%	108	5.95%	12	205
A referral was required but I didn't get one when I asked	10.89%	22	13.37%	27	70.30%	142	5.45%	11	202
Don't need the full number of appointments as I felt better quickly	4.58%	9	7.56%	15	81.31%	163	0.87%	13	198
Other	30.29%	62	5.63%	4	49.30%	98	14.03%	10	7

Consumers were asked about what did not appear to be a contributing factor to them disengaging from services. They provided the following responses as not being a contributing factor: my family was included and I didn't like that (80%, n=160), I felt better and had recovered (79%, n=162), decided my family or close friends would support me better (77%, n=156), and didn't include my family/carer (75%, n=152) (Figure 15, Table 13).

Reason	Major contributing reason (%)	Somewhat contributing reason (%)	Not a contributing reason (%)	Unsure (%)
Didn't listen...	50	10	20	20
I felt judged...	45	10	25	20
Didn't...	45	10	25	20
I felt I had...	40	10	25	25
I didn't feel...	40	10	25	25
I didn't trust...	20	10	25	45
I was...	20	10	25	45
Made me...	20	10	25	45
Decided to...	20	10	25	45
Other	10	10	25	55
Didn't...	10	10	25	55
Peer support...	10	10	25	55
Community...	10	10	25	55
I felt better...	10	10	25	55
Decided my...	10	10	25	55
My family...	10	10	25	55

Table 13: Consumers - Personal reason for disengagement

Contributing Factor	Major contributors	Somewhat contributors	Not a contributor	Unsure	Total				
Didn't listen to me	63.55%	113	35.12%	63	20.88%	44	0.47%	1	211
I felt judged / stigmatized by them	47.20%	101	22.43%	48	29.44%	83	0.93%	2	214
Didn't include/collaborate with me	48.93%	95	27.01%	48	30.05%	84	1.44%	3	209
I felt I had little say or control in making decisions	41.55%	86	36.50%	54	30.92%	84	1.45%	3	207
I didn't feel safe there	40.09%	85	13.57%	40	39.19%	83	1.89%	4	212
I didn't trust them	38.85%	82	24.64%	52	35.07%	74	1.42%	3	211
I was forgotten about	32.21%	67	21.93%	45	44.23%	92	1.92%	4	208
Made me repeat my story too much	29.47%	61	27.98%	56	42.03%	87	1.45%	3	207
Decided to stop because another service was better for me	24.51%	50	20.10%	41	51.47%	105	3.92%	8	204
Didn't include my family/caregiver	11.85%	24	7.92%	16	75.28%	152	8.95%	10	202
Peer support worker was best suited to my needs	10.84%	22	11.33%	23	69.68%	142	7.88%	16	203
Community support groups were best for me	9.41%	19	15.35%	31	88.51%	139	6.44%	13	202
I felt better and had recovered	7.89%	16	9.27%	19	78.02%	182	3.90%	8	206
Decided my family or close friend supported me better	5.90%	14	11.82%	24	78.85%	158	8.43%	9	203
My family was included and I don't like that	5.50%	11	9.50%	19	80.00%	180	5.00%	10	200
Other	10.44%	18	6.94%	8	88.33%	42	18.26%	11	72

- General Practitioner 59% (n=132)
- Psychologist 55% (n=124)
- Psychiatrist 39% (n=88)
- Peer worker 31% (n=70)
- Counsellor/therapist 30% (n=67)
- Public community mental health 18% (n=41)
- Private psychiatric hospital 18% (n=41)
- Social Worker 16.5% (n=37)
- Public mental health inpatient unit 6% (n=13)
- Other 5% (n=12)
- Headspace 4.5% (n=10)
- None 3.5% (n=8)
- Other suggestions included:
 - Colleagues, friends or family (n=5)
 - Assistance dog (n=1)
 - Non-Government Organisations (n=1)
 - Family (Sexual) Health Service (n=1)
 - Family violence and AOD workers (n=1)
 - General hospital (n=1)
 - Neuropsychiatrist (n=1)
 - Occupational Therapist (n=1)
 - One door Mental Health (n=1)
 - Private outpatients' group (n=1)
 - Support Workers (n=1)
 - Drop-in centre (n=1)
 - CAT team (n=1)

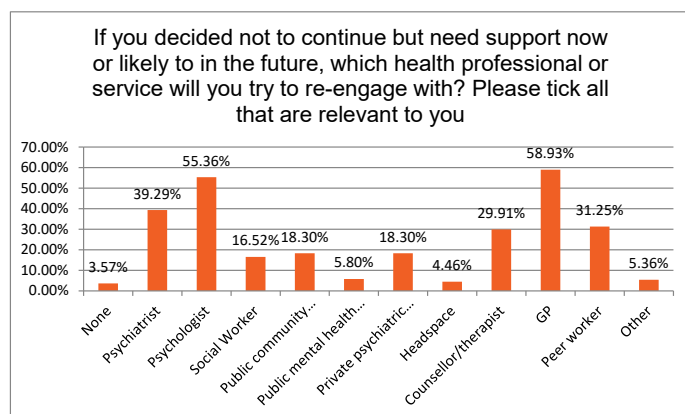


Figure 16: Consumers - Future access to mental health support

Consumers were asked what people do/what happens to them when they disengage with services from their personal experience, with 194 people providing further comments. The most frequently identified themes in priority order were:

- Mental health relapses or deteriorates further (n=115)
- Suicide attempt, self harm or risky behaviour (n=42)
- Find an alternative service (n=27)
- Are isolated or isolate themselves (n=25)
- Lose hope, faith or feel worthless (n=21)
- Have impacts on family, friends, employment and/or study (n=16)
- Find ways to support themselves (n=16)
- Hospitalisation (n=12)
- Increased use of drugs/alcohol or self-medicating (n=11)
- Have difficulty re-engaging in future (n=7)
- End up in the criminal justice system (n=5)
- Seek support from family, friends, carers (n=5)
- Stop taking medications (n=3)

The further comments provided suggested that many consumers were adversely impacted by disengaging with some experiencing significant crisis and trauma. Many just strove to find other ways to self-manage, not always successfully, on their own without supports.

Carer Responses:

Family/carers overwhelming said that disengagement with mental health services is an issue for a lot of people, with 91.3% of people (n=84) saying 'yes'. Of note, 71 respondents made further comments, this being a greater number providing additional qualitative comments than almost any other question within this survey, except Q61 (suggestions for what would help engagement). They identified several reasons for their views, noting lack of a caring approach, cost, service communication problems, long wait-times, lack of trust in services, lack of follow-up and service continuity, lack of meaningful links to community supports beyond clinical care.

Thinking about the health professional or service, the major contributors to disengagement were described by family/carers as: the service not offering the type of support that the person needed; care that didn't seem to be going anywhere/ lack of plans/goals; limited choice of service providers in their area; and that the service didn't meet the needs of the person they support (Figure 17).

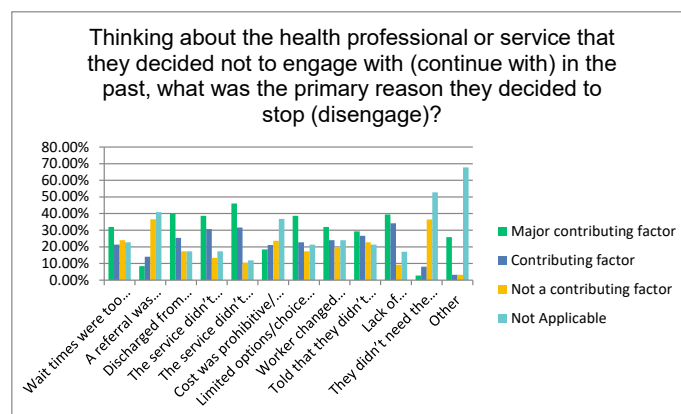


Figure 17: Carers - Primary reason for disengagement

Table 14: Carers - Primary reason for disengagement

Contributing Factor	Major contributing factor	Contributor	Not a contributor	Not Applicable	Total				
Wait times were too long	32.00%	24	21.33%	18	24.00%	18	22.67%	17	75
A referral was required but they didn't get one when they asked	8.45%	8	14.06%	10	39.52%	26	40.65%	29	71
Discharged from mental health professional/mental health service with no follow-up	40.00%	30	25.33%	18	17.33%	13	17.33%	13	75
The service didn't meet their needs (ending care)	38.61%	29	30.67%	23	13.33%	10	17.33%	13	75
The service didn't offer them the right type of support that they needed	48.05%	38	31.33%	24	10.83%	8	11.84%	9	75
Cost was prohibitive/ they couldn't afford to pay for it	18.42%	14	21.05%	16	23.68%	18	36.84%	28	75
Limited options/choice of service providers in their area	38.61%	29	22.67%	17	17.33%	13	21.33%	16	75
Worker changed frequently/ no consistent worker	32.00%	24	24.00%	18	20.00%	15	24.00%	18	75
Told that they didn't need/ longer wait times of the service	29.33%	22	26.67%	20	22.67%	17	21.33%	16	75
Lack of plan/goals/ didn't seem to be progressing/ going anywhere	36.47%	30	34.21%	26	9.21%	7	17.11%	13	75
They didn't need the full number of appointments as they felt better quickly	2.70%	2	3.11%	6	38.49%	27	52.70%	39	74
Other	28.81%	8	3.23%	1	3.23%	1	87.74%	21	31

Eighteen respondents provided further comments, emphasising a range of reasons for service disengagement. Again, these included cost, long wait-times for support, lack of follow-up, access to the right services to support needs, and lack of holistic care.

From a personal perspective, the major contributors to disengagement were described by family/carers as the person they support felt judged/stigmatised; services didn't listen to them; they were forgotten about; and they didn't trust services (Figure 18, Table 15).

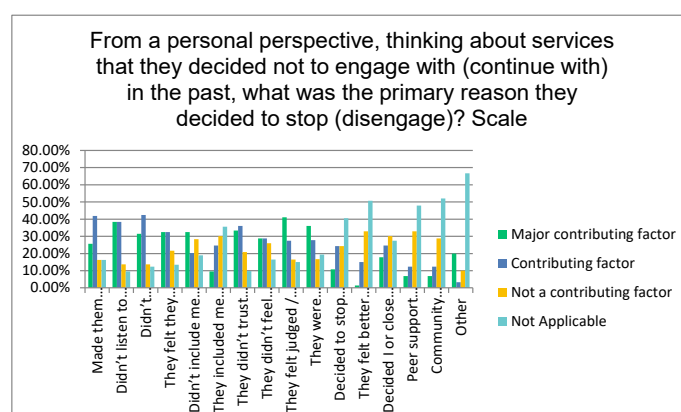


Figure 18: Carers - Personal reason for disengagement

Table 15: Carers - Personal reason for disengagement

Contributing Factor	Major contributor	Contributor	Not a contributor	Not Applicable	Total				
Made them repeat their story too much	26.68%	19	41.62%	31	16.72%	12	74		
Didn't listen to them	38.38%	28	38.38%	28	13.12%	10	8.62%	7	73
Didn't include/collaborate with them	31.61%	23	42.47%	31	13.12%	10	12.33%	9	73
They felt they had little say or control in making decisions	32.43%	24	32.43%	24	21.62%	16	13.91%	10	76
Didn't include me as their family member	32.43%	24	20.27%	15	26.26%	21	13.92%	14	74
They included me but they didn't see that	0.00%	0	34.66%	45	50.14%	22	16.92%	16	73
They didn't trust them	33.33%	24	36.11%	26	20.23%	15	9.72%	7	72
They didn't feel safe there	28.77%	21	28.77%	21	26.03%	19	16.44%	12	73
They felt judged / stigmatised	41.10%	30	27.40%	20	16.44%	12	15.07%	11	73
They were forgotten about	36.11%	26	27.78%	20	16.67%	12	16.44%	12	72
Decided to stop because another service was better for them	10.81%	8	24.32%	18	24.32%	18	40.94%	30	74
They felt better and had recovered	1.27%	1	16.67%	11	32.03%	24	60.99%	37	70
Decided to close friends supported them better	17.81%	13	24.69%	18	30.14%	22	27.40%	20	73
Peer support worker was best suited to their needs	6.08%	4	12.32%	9	30.08%	24	47.58%	36	72
Community support group were best for them	6.08%	4	12.32%	9	28.77%	21	52.08%	38	70
Other	20.00%	15	3.33%	3	10.00%	8	66.67%	50	30

Eighteen respondents provided further comments, emphasising several interpersonal experiences that led to disengagement. These included a loss of confidence in the service's ability to help them, the trauma induced by having to repeat their story, and a focus on medical treatments in the absence of other supports for broader recovery.

So many people think they are ok, take themselves off their meds and everything can bubble along ok for a period. But when stressors lift; work, financial, relationships, family, then the wheels can fall off and the second and subsequent dips can get progressively worse.

- Consumer Comment

I spiralled out of control. My world crashed down, I was helpless, suicidal, and utterly lost. It was traumatic.

- Consumer Comment

2.7 What would support re-engagement with services/health professionals?

Summary:

Almost half of consumer respondents (46%, n=199) and over half of carer respondents (55%, n=72) provided suggestions on what would help them or the person they care for to stay engaged with health professionals or services, or return to them to receive support.

Consistent themes across both groups of respondents included quality of providers, better trained staff, having peer workers available, consistent and coordinated support, accessibility and availability of service, more persistent follow up from the service and being listened to. Consumers also commented on affordability of the services, collaboration, and communication between health professionals, and being involved in decisions about their care. Carers added further comments regarding health professionals having more empathy, involving families better, providing more holistic care and systems level consistency and coordination.

For those who have disengaged from a service, consumers provided suggestions on how the service could better re-engage with them with feedback including directly contacting people (phone, text, email, letter or visit), follow up and finding out why they disengaged, providing higher quality services to prevent disengagement from occurring and providing access to peer workers or peer groups. Some consumers also commented on the need for regular and proactive outreach to consumers and more compassionate care that fits with consumers' needs. Carer responses also included providing more choices, providing access to peer support workers, listening and asking people what they want and need, demonstrating accountability for mistakes and improving system problems, providing more holistic care, providing more support in the community and reducing stigma within the system.

Consumer Responses:

Consumers were asked “what do you think would help people stay engaged with health professionals or services or return to a health professional or service to receive support for their mental health?”. A total of 199 responses were received. The most frequent suggestions (in order of highest frequency) included:

- Affordable services (n=47)
- Quality of providers or better trained staff (n=39)
- Having peer workers available (n=30)
- Accessible services (n=29)
- Consistency in providers/health professionals (n=28)
- Having follow up from the service (n=23)
- Being listened to (n=16)
- Collaboration/communication between health professionals/providers (n=13)
- Being involved in decisions about my care (n=16)
- Being educated on services available or processes to access (n=10)
- Less stigma from providers or regarding mental health (n=9)
- Not having to repeat my story (n=9)
- Improved relationships (n=8)
- Access to referrals (n=7)
- Improved funding for mental health services (n=7)
- Trauma informed and person-centred care (n=7)
- Having a choice of providers (n=7)
- Reduced waiting times (n=6)
- Smaller case loads of staff (n=5)
- Improved support and options for rural areas (n=5)
- Ease of re-engagement (n=4)
- Non-judgemental providers (n=5)
- Availability of hubs or one-stop-shop for long term/complex support (n=3)
- Access to specialised providers (n=3)
- Advocacy support, making complaints safely (n=2)
- Accountability of providers (n=2)

Figure 19 below is a word cloud with the most frequently used words regarding what would support consumers to stay engaged with mental health services. The larger the word, the more frequently it was identified by consumers. This also highlights the need for affordable, consistent, accessible, and professional mental health services including access to peer workers as the highest-ranking suggestions from consumers.



Figure 19: Consumers – what would support ongoing engagement with services

Consumers were asked for their suggestions on how services could best re-engage with people who have disengaged with mental health support from services. In total 180 consumers provided feedback. The most frequently identified themes in priority order were:

- Directly contact people (phone, text, email, letter, visit) (n=72)
- Follow up, find out reasons for disengagement (n=41)
- Provide higher quality services to prevent disengagement (n=21)
- Provide peer workers or peer groups (n=21)
- Seek feedback from consumers (n=19)
- Offer alternative support options (n=18)
- Listen to consumers (n=17)
- Have regular check-ins (n=15)
- Provide more mental health hubs, community programs, community groups (n=13)
- Make services more affordable (n=12)
- Advertise/educate on what support is available (e.g. radio, TV, etc) such as seeing your GP (n=7)

Carer Responses:

Over half of family/carers respondents (n=72) provided suggestions about what would help people stay engaged with health professionals or services or return to them to receive support for their mental health. Their suggestions included: having more empathy and including staff skills, using more peer support across the service system, involving families better, providing more holistic care, improved availability of services, listening, being more persistent with follow-up, and being more consistent and coordinated at a systems level.

Sixty-one family/carers respondents provided comments about what would help the person to re-engage with service where they had previously disengaged from them, and 65 family/carers respondents provided comments about how services could best re-engage with people. Their suggestions included: providing more choice; using peer support workers more; listening and asking people what they want and need; demonstrating accountability for mistakes and improving system problems; providing more holistic care; providing more support in the community; and reducing stigma within the system.

Figure 20 below is a word cloud with the most frequently used words regarding what would support the person they are for to stay engaged with mental health services. The larger the word, the more frequently it was identified by carers.



Figure 20: Carers – what would support ongoing engagement with services

2.8 Communication and collaboration between health professionals/services:

Summary:

Over 50% of both consumer and carer respondents reported no communication or coordination between health professionals and/or services they had accessed. There was consistency between the ratings of both consumers and carers with over 30% of each group identifying that the consumer fell through the gaps, had to retell their story with each contact, did not having a consistent person/contact, were not being clear about who to contact for help, and had received a lack of referrals.

Consumer Responses:

Consumers were asked about the communication and collaboration that they had experienced between health professionals and/or services, with 189 consumers responding to the question. 53% (n=100) identified no coordination, 47% (n=89) felt they fell through the gaps, 39% (n=73) had to re-tell their story multiple times, with their situation, needs or preferences not being remembered, 37.5% (n=71) stated they did not have a consistent person who they could contact or speak to and 36.5% (n=69) were not clear who to contact if they needed to (Figure 21, Table 16).

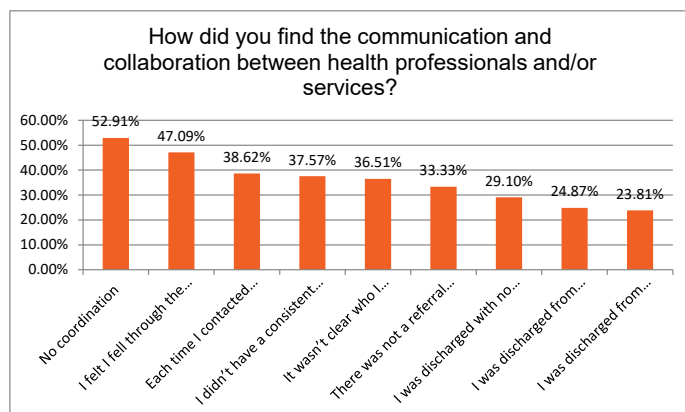


Figure 21: Consumers – health professional collaboration/communication

Table 16: Consumers – health professional collaboration/communication

Answer Choices	Responses	
No coordination	52.91%	100
I felt I fell through the gaps	47.09%	89
Each time I contacted them for help, I had to retell my story / they didn't seem to remember my situation, needs or preferences	38.62%	73
I didn't have a consistent person who I could contact or speak to	37.57%	71
It wasn't clear who I could contact when I needed to	36.51%	69
There was not a referral to other services	33.33%	63

I was discharged with no other option	29.10%	55
I was discharged from hospital with no referral or follow up	24.87%	47
I was discharged from community services before I was ready	23.81%	45

Carer Responses:

Carers were asked about the communication and collaboration that the person they support had experienced between health professionals and/or services, with 71 carers responding to the question. 53.5% (n=38) identified no coordination, 46.5% (n=33) weren't clear on who to contact when they needed to, 43.5% (n=31) had no referral to other services, 43.5% (n=31) had to retell their story each time they contacted the service, 42% (n=30) were discharged with no other option, 39.5% (n=28) fell through the gaps, 35% (n=25) were discharged from community services before they were ready, 35% (n=25) didn't have a consistent person or contact and 33.8% (n=24) were discharged from hospital with no referral or follow up (Figure 22, Table 17).

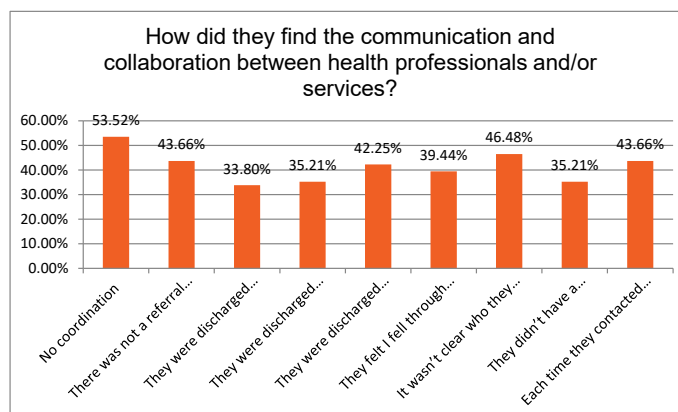


Figure 22: Carers – Communication and collaboration between health professionals and/or services

Table 17: Carers – Communication and collaboration between health professionals and/or services

Answer Choices	Responses	
No coordination	53.52%	38
It wasn't clear who they could contact when they needed to	46.48%	33
There was not a referral to other services	43.66%	31
Each time they contacted them for help, they had to retell their story / they didn't seem to remember their situation, needs or preferences	43.66%	31
They were discharged with no other option	42.25%	30
They felt I fell through the gaps	39.44%	28
They were discharged from community services before they were ready	35.21%	25
They didn't have a consistent person who they could contact or speak to	35.21%	25
They were discharged from hospital with no referral or follow up	33.80%	24

2.9 Discharge Notice:

Summary:

Approximately one third of consumers (33%, n=72), and more than one third of carers (39%, n=82) said that the health professional or service did not give them sufficient notice of impending discharge, and 28% (n=60) of consumer respondents and 33% (n=27) of carer respondents were unsure if enough notice was provided. From the comments received by both consumers and carers, lack of discharge communication (to the person, family or other service providers) was a common issue. Carers also noted a lack of family involvement. Some consumers, particularly those accessing private services commented positively about discharge with it either being known upfront or was identified and discussed well before discharge.

Consumer Responses:

Consumers were asked if they were given enough notice from the health professional or service about their impending discharge, where 39% (n=83) agreed, 33% (n=72) disagreed and 28% (n=60) were unsure (Figure 23). In analysing the comments provided by 123 consumers, 28 talked about negative experience where little or no notice was provided; often discharge happened abruptly. There were 36 consumers who provided commented on positive experiences where either the discharge timeframe was known upfront (e.g. 8 funded sessions, support available until a particular age range, hospitalisation for specific period of time), or was identified and discussed well before discharge occurred.

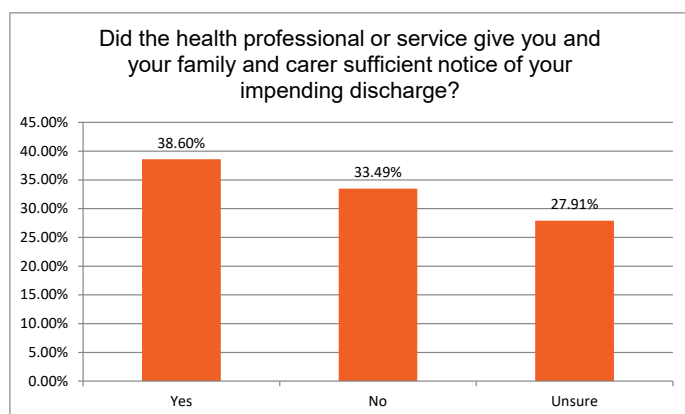


Figure 23: Consumers – Notice timeframe regarding discharge

Carer Responses:

More than one third of family/carer respondents (39.02%, n=32) said that the health professional or service did not give them sufficient notice of the person's impending discharge; approximate one third of respondents (32.93%, n=27) were unsure (Figure 24). Fifty-one respondents provided further comments. A prominent theme was the lack of discharge communication provision to the person, the family or to other service providers; lack of family involvement was particularly noted.

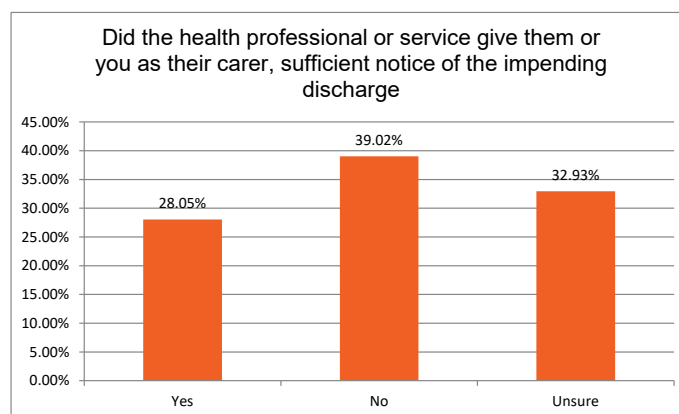


Figure 24: Carers – Notice timeframe regarding discharge

What happens when you experience a mental crisis in the middle of the night? Not a lot of after hours support services and even then - I don't have the funds to pay

- Consumer comment

They give up or they have family and friends who fight hard for them. But too often it is left up to family and friends and they have their own trauma from the experience.

- Carer Comment

2.10 Contributing factors to deterioration in mental health resulting in crisis:

Summary:

At least two thirds of both consumer and carer respondents identified not being able to access support when they needed it as the biggest factor contributing to deterioration in mental health, often resulting in crisis. Consumers also noted factors contributing to deterioration resulting in crisis including social issues, not being connected to existing services, regular health professional not being available, not having a regular health professional to access for help, and not being able to afford help. Carers had similar ratings identifying contributing factors as not being connected with existing services, wait times, unhelpful services, and problems with access to support (particularly those in rural areas).

For consumers who found themselves in a crisis, almost half 46% (n=107) sought help from an emergency department, and almost two thirds of carers 62% (n=48) said the person they care for sought help from an emergency department. For consumers who were discharged without admission to a hospital ward, 63% (n=67) went home after discharge, 48% (n=51) had no further follow up and 42% (n=45) had no referral to a mental health service, and 32% (n=34) had no referral to a health professional. Carers reported that for the person they care for, when they were discharged without admission into the hospital, they sought help from an emergency department and were discharged without being admitted to a hospital ward, 22% went home (n=10), 18% went to family or friends (n=9) and 18% received no follow up (n=9).

Thirty nine consumers who presented to an emergency department commented on their experience identifying issues including experiencing stigma, staff dismissing their needs as either 'too hard' or not serious enough, and many accounts of fragmented coordination of follow up after discharge. Twenty-six carers provided further comments, with most emphasising that following discharge, adverse consequences then ensued for the person and often for the family.

Consumer Responses:

At least 64% (n=133) of consumer respondents identified not being able to access support when they needed it as a key contributing factor to deterioration of their mental health resulting in crisis. Other responses included social issues (42%, n=87), not being connected to existing services (41%, n=86), regular health professional not being available (69%, n=87) and not having a regular health professional to access for help (34%, n=71) (Figure 25, Table 18). Other contributing factors identified by consumers included that they couldn't afford help (n=15), they were unable to access support that was needed (n=11), experiencing inappropriate treatment by the service/health professional (n=8), family or work issues (n=6), lack of

support from helplines (n=4), waiting lists (n=2), and drugs and/or alcohol problems (n=2). COVID, housing, social anxiety and language and cultural barriers were also identified by some consumer respondents.

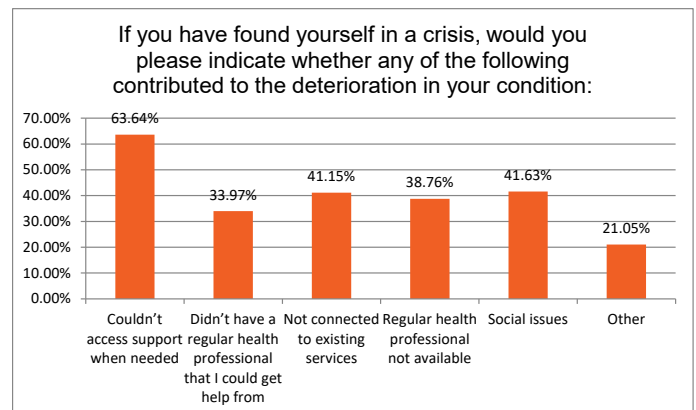


Figure 25: Consumers – contributing factors to mental health deterioration

Table 18: Consumers – contributing factors to mental health deterioration

Answer Choices	Responses	
Couldn't access support when needed	63.64%	133
Didn't have a regular health professional that I could get help from	33.97%	71
Not connected to existing services	41.15%	86
Regular health professional not available	38.76%	81
Social issues	41.63%	87
Other	21.05%	44

For consumers who did find themselves in a crisis, sought help from an emergency department and were discharged without being admitted to a hospital ward, 63% (n=67) went home after discharge from the emergency department, 48% (n=51) had no further follow up, 42% (n=45) had no referral to a mental health service, and 32% (n=34) had no referral to a health professional (Figure 26, Table 19).

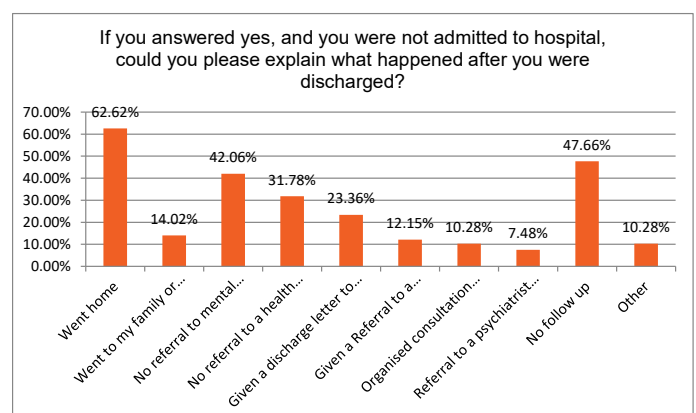


Figure 26: Consumers – after discharge

Table 19: Consumers – after discharge

Answer Choices	Responses	
Went home	62.62%	67
Went to my family or friends	14.02%	15
No referral to mental health services	42.06%	45
No referral to a health professional	31.78%	34
Given a discharge letter to my GP	23.36%	25
Given a Referral to a community mental health service	12.15%	13
Organised consultation with community mental health team	10.28%	11
Referral to a psychiatrist or psychologist	7.48%	8
No follow up	47.66%	51
Other	10.28%	11

39 consumers provided further comment to this question outlining the difficulties they had experienced either in the emergency department or on discharge from that setting. Their comments included experiencing stigma, services dismissing their needs as either ‘too hard’ or not serious enough, and accounts of fragmented coordination of follow-up after leaving.

Carer Responses:

More than two thirds of family/carers respondents (69.44%, n=50) said that not being able to access support when needed contributed to the person’s condition deteriorating when they found themselves in a crisis, and half of respondents (50%, n=36) said not being connected with existing services also contributed (Figure 27, Table 20).

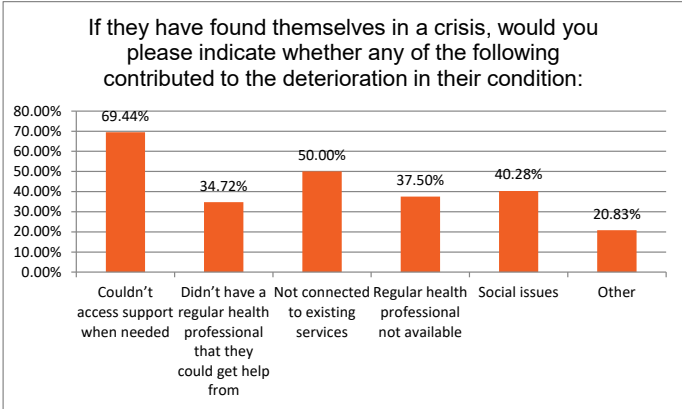


Figure 27: Carers – contributing factors to deterioration in mental health

Table 20: Carers – contributing factors to deterioration in mental health

Answer Choices	Responses	
Couldn't access support when needed	69.44%	50
Didn't have a regular health professional that they could get help from	34.72%	25
Not connected to existing services	50.00%	36
Regular health professional not available	37.50%	27
Social issues	40.28%	29
Other	20.83%	15

Twenty-eight respondents provided further comments. Wait-times, unhelpful services, and problems with access to support (particularly for those in rural areas) were prominent contributors to deterioration in their conditions when in crisis. Some comments also suggested that the person’s mental ill-health at the time was also a contributor for some. Almost two thirds of family/carers respondents (62.34%, n=48) said the person sought help from an Emergency Department when in crisis. When asked further what happened next if the person was not admitted to hospital but instead discharged, the most prevalent responses were that: some went home (22%, n=10); went to family or friends (18%, n=9); or received no follow-up (18%, n=9). Fewer respondents stated that: no referral was made, the person was given a discharge letter to their GP, or they were referred to a community mental health team, psychiatrist, or psychologist. Twenty-six respondents provided further comments, with most emphasising adverse consequences which then ensued for the person and often for the family.

“

There have been times where I’ve been forced to go to emergency services for mental health and then discharged after waiting several hours because I’m considered too difficult or I’ve had too many problems.

”

- Consumer comment

2.11 Mental Health Services that cannot currently be accessed:

Summary:

We asked respondents if there were any services they or the person they care for would like to access for their mental health and wellbeing but currently cannot access. In response, 182 consumers and 65 carers provided further comment. Both consumers and carers identified the need for more psychosocial-focussed and recovery-oriented support. Consumers also identified the need for peer support or peer workers, increased subsidies to access support, a psychiatrist that is affordable, a psychologist/clinical psychologist and mental health hubs, drop-in centres or community support programs. Carers' suggestions also included the need to address current system gaps.

Consumer Responses:

We asked consumers if there are any services they would like to access to support their mental health and wellbeing that they cannot access at the moment. In total 182 consumer respondents provided comment. The key themes that emerged from the comments in order of highest frequency included:

- Peer support / peer workers (n=34)
- Increased subsidies to access support/services (n=29)
- Psychiatrist that is affordable (n=24)
- Psychologist / clinical psychologist (n=25)
- Hubs or community support groups (n=25)
- Group therapy or group programs (n=12)
- Trauma informed support (n=11)
- Social support, social groups, social skills (n=10)
- Art therapy (n=9)
- Crisis support as an alternative to hospitals (n=9)
- Dialectical Behaviour Therapy – DBT (n=9)
- Exercise programs for people with a mental illness (n=8)
- Support for eating disorders and/or dieticians (n=5)
- In person support (n=5)
- Ongoing counselling (n=5)
- NDIS packages and/or support accessing NDIS (n=4)
- Preventative support (n=3)

Some of the comments provided by consumers included more psychosocial-focused and recovery-focused supports; however, they also noted the costs of services as a concern.

Carer Responses:

Sixty-five family/carers provided comments about the services they thought the person would like to access to support their mental health and wellbeing that they could not currently access. Most suggestions were associated with psychosocial and holistic recovery-oriented support in the community, and some related to addressing current systems gaps.

2.12 Use of Private Mental Health Services/Hospitals:

Summary:

Over half of consumers 52% (n=75) and a third of carers 32% (n=17) identified that the person accessing mental health supports has private health insurance. When asked if they were able to access private hospital services when they needed to, almost two thirds of consumers were able to 63% (n=49), however carers rated opposite to this with 84% (n=41) stating that they were not able to.

What has been most useful for consumers in accessing private hospital care included ease of access, higher quality services/care, a calm and welcoming environment, privacy, freedom, support, access to services, groups, therapies, day programs and 24/7 support. Carers commented on the regular follow up from psychiatrists, accessibility including early access to prevent relapse/crisis, and privacy.

Private services that are most frequently used as reported by both consumers and carers/families include private psychiatrists, psychologists, private hospital services and outpatient and/or day programs.

Consumer Responses:

There were 145 consumers who identified as using private mental health services or private hospitals. Of these, 52% (n=75) have private health insurance and 48% (n=70) do not. This suggests that many consumers are prepared to pay out of pocket costs to access private mental health services, without having private cover.

When asked if they were able to access private hospital services when they needed to, 63% (n=49) of consumer respondents for whom this question was applicable said 'yes' and 37% (n=29) said 'no'.

Consumers (n=54) provided further comment on what has been most useful to them in accessing private hospital care. Responses included ease of access (n=10), better services/quality of care (n=7), caring, calm, welcoming environment (n=5), privacy, freedom and support (n=6), access to services, groups, therapies, day programs (n=5), and access to 24/7 support (n=3).

When asked if they were able to use their private health insurance to access the care needed, for those the question was applicable to, 71% (n=56) said yes and 29% (n=23) said no.

We asked consumers what private mental health services they currently rely on with 91 providing further comments. The most frequently identified services included private psychiatrists (n=39), private psychologists including clinical psychologist (n=29), private hospital services (n=18), outpatient and/or day programs (n=8).

Carer Responses:

When asked if the person they care for has private health insurance, one third of carers stated they did 32% (n=17), two thirds do not 66% (n=35) and one person was unsure 2% (n=1).

When asked if they were able to access private hospital services when they needed, most were not 83.67% (n=41) and 16.33% were (n=8).

Carers (n=11) provided further comment on what has been most useful to the person they care for in accessing private hospital care. Responses included immediate attention/care, regular follow up with a private psychiatrist, early intervention, privacy, and having respite from normal life to receive treatment.

When asked if the person they care for was able to use their private health insurance to access the care they need, two thirds were not 63.83% (n=30) and 17% (n=8) were and 19% (n=9) were unsure.

The survey asked what services their private health insurance covered for the person they care for that was most useful, responses included hospital admission, inpatient care/ programs, psychiatrist, psychologist, and pharmaceutical services.

At the moment I am not using any of the private mental health services, but if I need to go into hospital for mental issues I will not be covered as I am not in the top cover which I think is not fair. For the amount of money that we pay for health, I should be able to go first class into a private hospital.

- Consumer comment

3. Appendix 1- Survey Questions

Q1. In which state/territory do you live?

Victoria
South Australia
New South Wales
Queensland
Tasmania
Western Australia
Northern Territory
Australian Capital Territory

Q2. Are you located in a

Capital City
Regional Centre
Remote Town

Q3. Are you

Male
Female
Other

Q4. What is your age range?

under 20 years
20- 39 years
40- 49 years
50-59 years
60-69 years
70-79 years
80 years or above

Q5. Are you of Aboriginal or Torres Strait Islander descent?

Yes
No
Prefer not to answer

Q6. What is your country of birth if not Australia?

Q7. What language do you mostly speak at home?

English
Other (please specify below)

Q8. Are you completing this survey as a:

Consumer (someone with a mental illness or experience of mental ill-health)?
Carer or Family Member

Consumer Questions

Q9. Select from the following options the one which best describes what services, health professional or supports you have mainly used in the past 5 years for your mental health

Public mental health services/hospitals/community teams
Private mental health services/hospitals
My GP
Only used a Private Psychiatrist
A Psychologist, counsellor/therapist
Veteran supports
Peer support (organised or unorganised)
Telehealth
Online or digital resources or Apps
Other (please specify)

Q10. Please explain the main reasons why you use this as your primary source of mental health support? Rate each of the following reasons

Answer Choices a. Major Contributing Reason b. Contributing Reason c. Not a Contributing Reason d. Not Applicable

I don't have to wait too long to see someone
The service meets my needs
They don't make me repeat my story too much
They listen to me
They include/collaborate with me
I feel I have some say or control in making decisions
They include my family/carers
They respect my privacy if I don't want to include my family
I trust them
I feel safe there
I don't feel judged / stigmatised by them
I can afford to pay for this service
Limited options/choice of service providers in my area
I have a consistent worker
They are organised and coordinate the support services I need
They seem to have a clear plan/goals
I am able to see a worker whose gender is of my choosing
Other (please specify)

Q11. If you used digital resources or Apps, which of the following influenced your decision to commence an online course for mental health and wellbeing? (Select all that apply)

My health professional recommended that I do the course

My friends or family recommended that I do the course

It was convenient for me to access due to limited availability of other mental health services in my local area

It was convenient for me to access due to my limited availability to attend a face-to-face treatment

It was convenient for me to access outside of the normal consultation (business) hours

The cost of face-to-face services

I chose to remain anonymous and limit personal information shared

I wanted to control the level of contact I have with my service provider (e.g. no contact with doctor, only receive feedback via email)

I was on the wait list for other services

I previously used other services or treatments but was dissatisfied

I previously used or was still using other services but I wanted to try something new

I prefer to use digital services rather than face-to-face services

The reputation of the institutes providing the online course

The scientific evidence supporting the online course

Not Applicable

Other (please specify)

Q12. At the time when you enrolled into an online course, what other support or treatment were you receiving to manage or improve your mental health and well-being? (Select all that apply)

None

Another online program

Medication

Face-to-face therapy with mental health professional (e.g., psychiatrist, psychologist, social worker, mental health worker)

Group therapy (including as an outpatient in a hospital setting)

Participation in an exercise group subsidised under Mental Health Treatment Plan

Alternative medicine (e.g. naturopathy, homeopathy, acupuncture)

Not Applicable

Other (please specify)

Q13. If you didn't complete the online course, please indicate why: (Select all that apply)

I was not ready to commit to an online course at the time

I wanted to discuss it first with my health professional

I no longer felt that I needed to do the course

The cost of the course was too high

I accessed another service and/or started another treatment

I experienced technical difficulties

I didn't improve

Not Applicable

Other (please specify)

Q14. After you realised you needed support, were you able to access a mental health service or a health professional in a reasonable time?

Yes

No

Please Comment:

Q15. Were there particular qualities of the service that helped you to feel more comfortable engaging with them?

Yes

No

Please Comment:

Q16. Were there particular qualities of the health professional that helped you to feel more comfortable engaging with them?

Yes

No

Please Comment:

Q17. Were there particular things about them that made you feel uncomfortable and not want to engage with them?

Yes

No

Please Comment:

Q18. Did this health professional or service help you for the length of time you felt you needed?

Yes

No

Q19. If no, did you or the health professional or service make the decision to end your support?

Myself

Service

Other

Unsure

Please Comment:

Q20. If no, did/are you intending to find alternative help for your mental health issues?

Yes

No

Q21. Do you think that disengagement (stopping) use of mental health services is an issue for a lot of people?

Yes

No

Unsure

Please explain the main reasons for your response:

Q22. Did the health professional or service give you and your family and carer sufficient notice of your impending discharge?

Yes

No

Unsure

Please explain the main reasons for your response:

Q23. Thinking about the health professional or service that you decided not to engage with (continue with) in the past, what was the primary reason you decided to stop (disengage)?

Answer choices

- a. Major Contributing Reason
- b. Contributing Reason
- c. Not a Contributing Reason
- d. Unsure

Wait times were too long

A referral was required but I didn't get one when I asked

Discharged from mental health professional/mental health service with no follow-up

The service didn't meet my needs (wrong care)

The service didn't offer me the right type of support that I needed

Cost was prohibitive/ I couldn't afford to pay for it

Limited options/choice of service providers in my area

Worker changed frequently/ no consistent worker

Told that I didn't meet/no longer met criteria of the service

Lack of plan/goals/didn't seem to be progressing/going anywhere

Didn't need the full number of appointments as I felt better quickly

Other

Please comment:

Q24. From a personal perspective, thinking about services that you decided not to engage with (continue with) in the past, what was the primary reason you decided to stop (disengage)?

Answer choices

- a. Major Contributing Reason
- b. Contributing Reason
- c. Not a Contributing Reason
- d. Unsure

Made me repeat my story too much

Didn't listen to me

Didn't include/collaborate with me

I felt I had little say or control in making decisions

Didn't include my family/carers

My family was included and I didn't like that

I didn't trust them

I didn't feel safe there

I felt judged / stigmatised by them

I was forgotten about

Decided to stop because another service was better for me

I felt better and had recovered

Decided my family or close friends supported me better

Peer support worker was best suited to my needs

Community support groups were best for me

Other

Please comment:

Q25. How did you find the communication and collaboration between health professionals and/or services?

No coordination

There was not a referral to other services

I was discharged from hospital with no referral or follow up

I was discharged from community services before I was ready

I was discharged with no other option

I felt I fell through the cracks

It wasn't clear who I could contact when I needed to

I didn't have a consistent person who I could contact or speak to

Each time I contacted them for help, I had to retell my story / they didn't seem to remember my situation, needs or preferences

Q26. If you decided not to continue but need support now or likely to in the future, which health professional or service will you try to re-engage with? Please tick all that are relevant to you

None

Psychiatrist

Psychologist

Social Worker

Public community mental health

Public mental health inpatient unit

Private psychiatric hospital

Headspace

Counsellor/therapist

GP

Peer worker

Other

Please Comment:

Q27. If you have found yourself in a crisis, would you please indicate whether any of the following contributed to the deterioration in your condition:

Couldn't access support when needed

Didn't have a regular health professional that I could get help from

Not connected to existing services

Regular health professional not available

Social issues

Other

Please Comment

Q28. When you found yourself in a crisis, did you seek help through an emergency department?

Yes

No

Not Applicable

Q29. If you answered yes, and you were not admitted to hospital, could you please explain what happened after you were discharged?

Went home

Went to my family or friends

No referral to mental health services

No referral to a health professional

Given a discharge letter to my GP

Given a Referral to a community mental health service

Organised consultation with community mental health team

Referral to a psychiatrist or psychologist

No follow up

Other

Please Comment

Q30. What do you think would help people stay engaged with health professionals or services or return to a health professional or service to receive support for their mental health? Please tell us your ideas

Q31. What would assist/support people to re-engage with services where they had previously disengaged from them? Please tell us your ideas

Q32. From your experience, what do people do/what happens to them after they disengage with services? Please comment:

Q33. How do you think services could best re-engage with people who have disengaged with mental health support from services? Please tell us your ideas

Q34. What services would you like to access to support your mental health and wellbeing that you can't access at the moment? Please comment

Q35. If you use private mental health services and private hospitals do you have private health insurance?

Yes

No

Q36. If you use private mental health services and private hospitals, what services do you currently rely on? Please comment

Q37. Have you been able to access private hospital services when you needed to?

Yes

No

Not Applicable

Q38. If yes, what has been useful to you in accessing this private hospital care? Please comment

Q39. Have you been able to use your private health insurance to access the care you need?

Yes

No

Not Applicable

Q40. If yes, what services did it cover that were useful to you? Please comment

Q41. What services would you like to access that you can't access at the moment? Please comment

Q42. Why? Please comment

Carer Questions

Q43. Select from the following options the one which best describes what services, health professional or supports the person you support has mainly used in the past 5 years for their mental health

Public mental health services/hospitals/community teams

Private mental health services/hospitals

GP

Only used a Private Psychiatrist

A Psychologist, counsellor/therapist

Veteran supports

Peer support (organised or unorganised)

Telehealth

Online or digital resources or Apps

Other

Please Comment

Q44. Please explain the main reasons why they use this as their primary source of mental health support? Please tick all that are relevant

Wait times

The service meets their needs

They don't make them repeat my story too much

They listen to them

They include/collaborate with them

They feel they have some say or control in making decisions

They include me as family/carer

They respect their privacy if they don't want to include their family

They trust them

They feel safe there

They don't feel judged / stigmatised

They can afford to pay for this service

They have limited options/choice of service providers in their area

They have a consistent worker

They are organised and coordinate the support services they need

They seem to have a clear plan/goals

They are able to see a worker whose gender is of their choosing

Other

Please Comment

Q45. After you realised the person you care for needed support, were they able to access a mental health service or a health professional in a reasonable time?

Yes

No

Please Comment

Q46. Were there particular qualities of the service that helped them to feel more comfortable engaging with the service?

Yes

No

Please Comment

Q47. Were there particular qualities of the health professional that helped them feel more comfortable engaging with the health professional?

Yes

No

Unsure

Please Comment

Q48. Were there particular things about the health professional or service that made them feel uncomfortable and not want to engage?

Yes

No

Unsure

Please Comment

Q49. Did this health professional or service help them for the length of time you felt they needed?

Yes

No

Please Comment

Q50. If no, did they or the health professional or service make the decision to end their support?

Themselves

Service

Other

Unsure

Please Comment

Q51. If no, did/are they intending to find alternative help for their mental health issues?

Yes

No

Q52. Do you think that disengagement (stopping) use of mental health services is an issue for a lot of people?

Yes

No

Unsure

Please explain the main reasons for your response

Q53. Did the health professional or service give them or you as their carer, sufficient notice of their impending discharge

Yes

No

Unsure

Please explain the main reasons for your response

Q54. Thinking about the health professional or service that they decided not to engage with (continue with) in the past, what was the primary reason they decided to stop (disengage)?

Answer choices

a. Major Contributing Reason

b. Contributing Reason

c. Not a Contributing Reason

d. Not applicable

Wait times were too long

A referral was required but they didn't get one when they asked

Discharged from mental health professional/mental health service with no follow-up

The service didn't meet their needs (wrong care)

The service didn't offer them the right type of support that they needed

Cost was prohibitive/ they couldn't afford to pay for it

Limited options/choice of service providers in their area

Worker changed frequently/ no consistent worker

Told that they didn't meet/no longer met criteria of the service

Lack of plan/goals/didn't seem to be progressing/going anywhere

They didn't need the full number of appointments as they felt better quickly

Other

Please Comment

Q55. From a personal perspective, thinking about services that they decided not to engage with (continue with) in the past, what was the primary reason they decided to stop (disengage)? Scale

Answer choices

a. Major Contributing Reason

b. Contributing Reason

c. Not a Contributing Reason

d. Not applicable

Made them repeat their story too much

Didn't listen to them

Didn't include/collaborate with them

They felt they had little say or control in making decisions

Didn't include me as their family/carers

They included me but they didn't like that

They didn't trust them

They didn't feel safe there

They felt judged / stigmatised

They were forgotten about

Decided to stop because another service was better for them
They felt better and had recovered
Decided I or close friends supported them better
Peer support worker was best suited to their needs
Community support groups were best for them
Other
Please Comment

Q56. How did they find the communication and collaboration between health professionals and/or services?

No coordination
There was not a referral to other services
They were discharged from hospital with no referral or follow up
They were discharged from community services before they were ready
They were discharged with no other option
They felt I fell through the cracks
It wasn't clear who they could contact when they needed to
They didn't have a consistent person who they could contact or speak to
Each time they contacted them for help, they had to retell their story / they didn't seem to remember their situation, needs or preferences

Q57. If they decided not to continue but need support now or likely to in the future, which health professional or service do you think they will try to re-engage with? Please tick all that are relevant to them

None
Psychiatrist
Psychologist
Social Worker
Public community mental health
Public mental health inpatient unit
Private psychiatric hospital
Headspace
Counsellor/therapist
GP
Peer worker
Other
Please Comment

Q58. If they have found themselves in a crisis, would you please indicate whether any of the following contributed to the deterioration in their condition:

Couldn't access support when needed
Didn't have a regular health professional that they could get help from
Not connected to existing services
Regular health professional not available
Social issues
Other
Please Comment

Q59. When they found themselves in a crisis, did they seek help through an emergency department?

Yes
No
Not Applicable

Q60. If you answered yes, and they were not admitted to hospital, could you please explain what happened after they were discharged?

Went home
Went to family or friends
No referral to mental health services
No referral to a health professional
Given a discharge letter to their GP
Given a Referral to a community mental health service
Organised consultation with community mental health team
Referral to a psychiatrist or psychologist
No follow up
Other
Please Comment

Q61. What do you think would help people stay engaged with health professionals or services or return to a health professional or service to receive support for their mental health? Please tell us your ideas

Q62. What would assist/support people to re-engage with services where they had previously disengaged from them? Please tell us your ideas

Q63. From your experience, what do people do/what happens to them after they disengage with services? Please comment

Q64. How do you think services could best re-engage with people who have disengaged with mental health support from services? Please tell us your ideas

Q65. What services do you think they would like to access to support their mental health and wellbeing that they can't access at the moment? Please comment

Q66. Do they have private health insurance

Yes
No
Unsure

Q67. What services do they currently rely on? Please comment

Q68. Have they been able to access private hospital services when they needed to?

Yes
No

Q69. If yes, what has been useful to them in accessing this private hospital care? Please comment

Q70. Have they been able to use private health insurance to access the care they need?

Yes

No

Unsure

Please Comment

Q71. If yes what services did it cover that were useful to them? Please comment

Q72. What services would they like to access do you think that they can't access at the moment? Please comment

Q73. Why? Please comment



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