

The 'Missing Middle' Our Voices



Lived Experience
A U S T R A L I A

Companion document to:
The Missing Middle Lived Experience
Perspectives Research Report
January 2021

© Lived Experience Australia Ltd, 2021

ISBN: 978-0-6450753-2-8

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced by any process without prior written permission from Lived Experience Australia Ltd. Request and enquiries concerning reproduction and rights should, in the first instance, be addressed to Lived Experience Australia Ltd.

Lived Experience Australia Ltd
PO Box 542, MARDEN South Australia 5070, Australia
Telephone: 1300 620 042
Email: admin@livedexperienceaustralia.com.au
Website: www.livedexperienceaustralia.com.au

The suggested citation for this document is:

Kaine, C. & Lawn, S. (2021) The 'Missing Middle' Our Voices, Lived Experience Australia Ltd: Marden, South Australia, Australia.

Acknowledgements

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 transferred the data to create this report.

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

National Survey Advisory Committee

Lived Experience Australia
Janne McMahon, Chair
Suzie Adam, Carer
Lyn English, Consumer
Camilo Guaqueta, Carer
Samuel Hockey, Consumer
Darren Jiggins, Consumer
Sharon Lawn, Carer
Jane Meegan, Carer
Heather Nowak, Consumer
Norm Wotherspoon, Consumer

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 Report is the companion document to the full research report titled "The Missing Middle – Lived Experience Perspectives" both of which faithfully report 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

Contents

1. Introduction 2

2. Our Voices 3

2.1 Main Mental Health Services Accessed 3

2.2 Accessibility of services 5

2.3 Qualities of the service and health professional 7

2.4 Length of support provided 10

2.5 Disengagement from support 11

2.6 Discharge notice 17

2.7 What would support re-engagement with services/health professionals? 17

2.8 Contributing factors to deterioration in mental health resulting in crisis 19

2.9 Services for mental health that cannot currently be accessed 20

1. Introduction

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. 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. This report is a collection of the qualitative responses received from consumers, families and carers and should only be read in conjunction with the full research report titled "The Missing Middle- Lived Experience Perspectives".

When reviewing the survey results, researchers Ms Christine Kaine and Professor Sharon Lawn discovered that a large number of consumers, families and carers provided very detailed, and powerful accounts of their experiences within the mental health system in Australia.

While the main report outlines the findings from our analysis of survey results, we felt it was important to also publish the voices of consumers and those who support them so they are heard and to provide a clearer picture of real-life experiences regarding the current mental health system. As there were a significant number of comments provided, a selection has been included in this report, demonstrating many of the typical experiences described by consumers, families and carers. None of the responses are identifiable to ensure anonymity and privacy of survey respondents.

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>

2. Our Voices

2.1 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.

Why do you use your main mental health provider?

When asked why you use your selected mental health provider as your primary support, the following comments were provided by **consumers**:

- 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.*
- Long-standing relationship, even if they're not the greatest it's better the devil you know in some respects.*
- I was seeing a Psychiatrist in a public hospital, but when he told me to go with my panic attacks, I did not go back. I felt like I was going backwards with this person, so went back to my Doctor who has put me on the right path. He is now helping me get off a very addictive drug. I am very sensitive to anti depressants so it has been a roller coaster for many years.*
- The service is terrible, unsafe, inconsistent, I get prescribed a different medication every time I go there, I have been unable to obtain treatment that has helped me, I feel more damaged by public psychiatry.*
- LGBTQ+ friendly and specific treatment/therapy options.*
- I want to get better and come out of the system because the system sucks. The system is abusive, expensive and offers no privacy or respect for human beings.*
- I access mostly psychologists and public system because they are the only options available, even so they are barely available. By the time I am admitted to hospital, I usually have presented to A&E or crisis team many times in desperation (it is the last thing I do before suicide). It took over 6 months to get into the public program I am in now (for complex needs) and that consists of talking to someone once a week.*
- They have good contacts with private hospitals and associated doctors, so I can also get an admission if/when I require one.*
- The several local psychologists I've seen were all varying degrees of awful. Completely lacking in trauma informed practice and no idea of recovery oriented care. Plus the wait lists are 6+ months and they all have massive gaps.*
- Because they take care of my physical needs. They never dismiss my health issues and are on top of blood tests, they take me seriously about my physical needs and never put my physical issues down to mental illness. They are the best person I have ever had who attends to both physical and mental health.*
- I had a private psychiatrist who treated me appallingly and there was dereliction of duty of care to me. He was not interested in helping me reach goals, in fact he told me they were unrealistic.*
- I now have a new private psychiatrist and although he costs a lot more, he treats me from a holistic perspective. He puts me as the expert in my experiences and recovery. Nothing I could say to him would lead him to judge or stigmatise my experiences. I have just now come from my appointment with him and he marvelled at how well I am doing these days. He even congratulated me on working actively towards recovery.*
- Primarily I see a psychodynamic psychotherapist who is a psychiatrist. This is hard to afford as after medicare rebates, I am out of pocket about \$6,000 annually for the 2 - 3 weekly sessions that I need.*
- I also see a general psychiatrist, my GP, OTs, and I have other psychiatrists who admit me to private hospitals. I have to maintain top level private health cover for mental health admissions, which again is very expensive.*
- I've also been compulsorily admitted to public hospitals on multiple occasions, and I wouldn't recommend this. It's been very re-traumatising and counter-productive.*

- *I no longer see public health or psychologist. I was in crisis when I saw public health & no other options, then hospitalised. Both were a very traumatic & degrading experience so will not voluntarily go back to ask for help. Found that the psychologists I can afford (i.e. no gap fee) & short waiting list were not the right fit (unsuitable for severe MI, also I asked one to share ALL info with me, which she agreed to then went behind my back). I have had 2 psychologists where I was trying to build a relationship (in less than the 10 MBS sessions) so that I had a 'go to' when I was becoming unwell (to then use the remaining sessions). Didn't work & both have since left the area anyway (so my effort was fairly pointless).*
- *There are no services between psychologist (too ill) & community mental health (not ill 'enough', also VERY limited & unsuitable for me). I'm very low on trust after my experiences, & cannot tolerate information/decisions etc being done behind my back.*
- *I have been really fortunate to have had an ongoing support from a private psychiatrist for over 20 years, she does not charge me a large gap and no gap when I am unable to work. I have been incredibly lucky to have had this support, otherwise I would have struggled to access consistent support in the public system. I had an inpatient stay in a public mental health facility, and it did not meet my needs, nor was there any follow-up with either myself or my psychiatrist, despite this being offered by the service. I will do all I can to avoid the public mental health system from now on. I answered the questions above in relation to my appointments with my psychiatrist and counselling and psychology supports I have found myself. I would like to add that psychology services are now very difficult to access in South Australia, even with then 10 free Medicare funded sessions, as most psychology services charge a large, unaffordable gap and/or take months to get into see or space sessions too far apart to be of real benefit. I have found this to be a huge barrier to ongoing mental health supports, for myself and when I have assisted family members and friends to try and source a psychologist. One needs to be very persistent and I have seen those close to me give up trying to source counselling/psychology services, which is when I have made the many phone calls on their behalf. I can see that this would put many people off from continuing to seek help, one phone call is often too difficult for someone with mental ill health, to access these services usually takes multiple phone calls, which is difficult to manage with mental health symptoms. I would love to see a return of primary health prevention strategies, when all one had to do was make one call to a local primary health service and the call lead to a triage call and an initial appointment usually within 2-3 weeks.*
- *Most important reason I remain in control and make the decisions relating to my own mental health care, it the medical professionals attempts to take control I disengage and do not return.*

When asked why the person they support uses the selected mental health provider as their primary support, the following comments were provided by **carers**:

- *He feels heard and validated. He is recognised as the expert in his experience (as he is) and provided some strategies to try. This makes him feel safe and builds strong trust and expectations.*
- *My relative has chosen not to engage with services other than his GP as he does not trust them to help him.*
- *Clinician has an acknowledged lived experience, and this is important to building trust and hope.*
- *Once he found this psychiatrist, he has stayed with her for the past 12 years. Research shows this consistent client doctor relationship increases survival rates.*
- *They are located close to home which is really important because he doesn't drive very far on his own. Private psychiatrist is a good hour drive away and then there's the gap to be paid.*
- *We have limited choices in our area. Even the best can be judgemental, which is not useful and doesn't help us feel at ease with the service provider. We have to do quite a bit of homework to find someone who is respectful, listens, understands their own job properly.*
- *My son has no choice but to use the Public MH System, as they have placed him on an involuntary order. ...Even though my son appreciates his case worker, I would not say that he and myself (as his main carer/support worker) are very enamoured with the way the Public MH System, in general, works. Supports for my son have improved since NDIS has happened.*
- *The funding comes from the NDIS. If the person I care for didn't have a generous NDIS plan, he would not be able to afford this support as he is on the DSP.*

2.2 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 'handballing' responsibility to other providers, cost, stigma and dismissiveness by services, and the long wait times for follow-up with community supports were dominant themes.

Are you/the person you support able to access mental health services when it is needed within a reasonable timeframe?

When asked if they were able to access mental health services at the point they realised they needed it with within a reasonable timeframe, the following comments were provided by **consumers**:

- *It took months before I figured out the system, felt capable of making and attending an appointment. I never planned to see a psychologist or commence therapy, I was just fortunate that after 5+ GPs one realised something wasn't right and instead of giving me a script gave me care plan.*
- *It is very hard to get suitable support and usually I have found in the public system that they change every 12 - 18 months which means starting again which becomes very very difficult and hard especially as I don't have a 'run of the mill' type of MH diagnoses*
- *I see a psychologist but I am not getting the specialised care I need to manage anorexia and Fnd and extremely unwell and disabled and too unwell to leave the house. I need much more intensive and practical help which I won't available and I can't find a support coordinator through NDIS so have funding but no services.*
- *As a senior priority focus is on the younger generation or has a dementia focus, there is a difference between mental ill health due to changes in life circumstances, physical ill health and I found it offensive when health professionals automatically assess you for dementia.*
- *I initiated through my GP a private consultation with a Psychiatrist at a clinic and was diagnosed with PTSD. I was supposed to commence my EMDR therapy when Covid*

started and we went into lockdown. It was very difficult to communicate with this clinic, there was limited flexibility and the costs were very high and they weren't all that friendly... I reached out to a trusted friend who referred me to another private clinic and clinical psychologist. I was very fortunate that they accommodated me immediately as I was quite suicidal at the time.

- *After self harming I was taken to emergency of a public hospital. I was kept there for a day and sent to psych ward of a public hospital. Despite me telling them I had a private psychiatrist they did not contact him. I was kept there for the weekend and my mum was told by the treating psychiatrist that he was going to start all over again with me. Later in the day they finally transferred me to the usual private clinic I attend. The public hospital ward I was in was terrifying and not therapeutic at all.*
- *It was during the Covid 19 lockdown. I had been recently diagnosed with PTSD by a Psychiatrist at a private clinic and asked for telehealth services. They did not reply. I then asked again for urgent assistance and heard nothing back while still receiving other generated emails. I reached out to a friend who knew a good clinical psychologist and her private clinic booked me in immediately with home visits. I will be eternally grateful for this as I believe it prevented me from committing suicide.*
- *I eventually gained access to public mental health services outpatients several years ago and I received excellent treatment which included changing my medication. My mental health really improved after this, with the addition of a mild antidepressant. 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.*
- *Private psychologist is the only option available. It is one part of the treatment I need. Those with borderline personality disorder or those with trauma histories need specialist long term treatments, i.e. fully adherent dbt, from a variety of services. There are no accessible, holistic treatment services for bpd. This is not the 'missing middle', this is at the pointy end where those with serious and complex mental health conditions are stigmatised, retraumatised, and turned away. More funding for comprehensive long term bpd treatment, not just short term, token community psychosocial art initiatives - we need real treatment to stay alive.*
- *Except for my private psychiatrist, I have found it very challenging to access appropriate mental health support in a timely manner. It takes many many phone calls to find a psychologist, where the Medicare gap is affordable, in many cases, the practice requires up to \$150 to be paid after the visit, with between \$70-40 gap payable, so even if the gap is affordable, which it often isn't, having that amount of money available in my bank account to pay the fee is not possible, even if it refunded immediately, my limited funds, due to my difficulty with finding ongoing secure work, due to my mental health issue, means I cannot attend an appointment of this kind. Appointments where there is no gap or upfront fee, are often booked out months in advance.*

When asked if the person they support was able to access mental health services at the point they realised they needed it with within a reasonable timeframe, the following comments were provided by **carers**:

- *This is the pathway for support apparently.... taken to hospital by ambulance, eventually seen by ACT team after they cancelled twice, eventually referred to the [community service]. PHN Suicide prevention Pathway form filled in by doctor after leaving hospital. Two weeks later still nothing back after my son had two attempts on his life. The hospital had let him out at 3 am with no support and he attempted again within 12 hours.*
- *He was in crisis but the thought of waiting hours in an ED added significantly to his stress, so was unacceptable and there were no local services available (it was a Sat night).*
- *The GP was so responsive and, most important, puts the mental health and physical health together in every visit. Took quite a bit of searching to find a private psychiatrist whose books weren't full and then there was no guarantee that they would even be a good fit together, that my husband would trust and get along with them...and then of course it was another 4 month wait to even get the first appointment due to the wait time. Seemed to serve the business need and model of the psychiatrist rather than actually geared to people's needs re mental health.*
- *Wait times to access a psychologist are ridiculous. My daughter often backs out of help because the wait times are too long.*
- *Spent 48hrs in ER to come home under my care where I took 2 weeks off work for fulltime supervision. Only managed by GP in the end as no bed available in hospital even though willing to be admitted.*
- *Public services were essentially non-existent either as result of wait times which were estimated to between 8-12 months. Public hospitals and CAT teams were singularly inexperienced; didn't appear wanting to engage and when discovered had accessed private services used this as an opportunity to hand ball to those services without regard for capacity to financially maintain those private services.*
- *Delay because of being pushed from one service to another. Delay because wrong age. Delay because assessment team was new and not able to identify the issue. Delay because services didn't take on new patients in lead up to Christmas.*
- *Sometimes. I have found the more presentations to Hosp ED when in a crisis the less support is given.*
- *Provider not proactive, did not acknowledge seriousness of situation or urgency of need.*



2.3 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.

Are there particular qualities of the service that made you / the person you support feel more comfortable?

When asked if there were particular qualities of the service that made them feel more comfortable, the following comments were provided by **consumers**:

- *I haven't felt comfortable engaging with any service for many years.*
- *The therapist was the first therapist to engage with me as an individual rather than a diagnosis and did not enforce treatment but rather let me choose what I wanted to discuss and help I required.*
- *TIME available to discuss issues and events without feeling rushed and always booking next appointment for me, not me having to rely on my memory.*
- *My GP was very understanding, she treated it as if it were any other illness, wanted me to have blood tests done etc to ensure there wasn't an underlying cause for my mental health issues that was by far the best outcome I could have hoped for when initially seeking professional help.*
- *The first service I used I disengaged from due to the professional being harmful and medically negligent. However the service I use now, has a psychiatrist who is very warm and a sense of humour which helps me stay engaged.*
- *Lived experience!!! I can't stress this enough. I know that clinical approaches really steer away from bringing the practitioners personal mental health experience into the room. However, I have OCD and my psychologist also has a personal experience of OCD and being such a stigmatised condition, it was so valuable to know that she understood and I therefore felt way less shame and self stigma.*
- *I was just lucky that my psychiatrist called and just happened upon this person and it was a good fit for me. In many ways the service where she works is unhelpful because there is no support around it. If I have a hard session, there is nowhere for me to sit and recover and no safe spaces or people around to help. It's all super privatised.*
- *My psychologist was very caring and encouraged me to see myself differently than I did. She made me feel I was worthy of being alive.*
- *Cost is a barrier. Location is a barrier. Accessibility in terms of getting to the office, wait lists, layout, decor can all be barriers. Also services are often very paternalistic I found and I hated it. They thought they knew what I needed better than I did.*
- *Staff is a big one, especially for hospitals both public and private (I have seen all sorts of things, from staff stealing meds, patients threatening to kill you, to inappropriate actions from doctors - but if you report you just get kicked out - you become the trouble maker there is no real time safe guard - you can leave a note for official visitors but I have seen staff take them out/you also end up being 'blacklisted from a hospital - I know many people who have had this they just say there is never a bed available for you) there needs to be a secure way of contacting the right people who actually want to hear it rather than cover everything up.*
- *Going in to ED keeps me safe for the 6hrs that I am in deep distress. But it is a demoralising experience, with no support or kindness. I just sit with my headphones over my ears, but nothing playing. I sit with eyes closed waiting for my distress to settle, with no supports (as usual in my life). My*
- *This psychologist when I made the appointment through email sent me a couple of questionnaires and forms to fill out and send to her before our first appointment. This gave her a good idea as to my personality, history etc and she was spot on about me and what areas I needed to work on. She was very professional.*

psychosocial disability prevents me from reaching out in a crisis. Suicidal thoughts over 35 years are stubborn. Again I need to sit in a bean bag in a community centre with a Peer Worker checking in on me occasionally.

- *My first psychiatrist put me on strong medication which led to my being unable to work for two years. Our consultations were generally about medication. I did not get any better.*
- *I had to see different people all the time, all with different approaches, attitudes and constantly having to repeat my 'story'. Irregular times for appointments.*

When asked if they were particular qualities of the service that made the person they support feel more comfortable, the following comments were provided by **carers**:

- *Being listened to, understanding, empathy, discussions with our person, us and everyone involved, collaboration, no judgement or stigmatisation, working together with Community Mental Health case manager, support coordinator, support workers, carer/support person/family member and having good communication between all - having people working with us who are passionate, committed, empathetic, understanding, are genuinely caring, and are willing to go the extra mile to get the best outcomes - they do their job properly and are dedicated.*
- *Friendly and not judgmental attitude is one key point for engagement. Someone who is interested in undertaking our story before applying professional knowledge over our lives.*
- *Being treated with respect, which has always happened.*
- *Felt listened to and safe.*
- *They listened to his needs, spent time building rapport, welcoming and friendly. Accessible via*
- *Varying means, email, phone, tele health.*
- *The providers validated his experience rather than questioned it.*

Are there particular qualities of the health professional that made you / the person you support feel more comfortable?

When asked if they were particular qualities of the health professional that made them feel more comfortable, the following comments were provided by **consumers**:

- *Yes, I guess initially my doctor's personalities and how much of a 'match' they were/are for me. My psychologist and I, I thought clicked straight away, I immediately found her nice, understanding and helpful. Similarly with the neuropsychologist she seemed very nice and calm and wanted everything to be clear and simple. Unfortunately my psychiatrist experience wasn't a fit. She believed in very different ways of recovery than what I wanted. So I guess views need to align, you need to find the right type of professional to bother seeing them. I kind of wish I knew before that's what she was like or I would have picked someone else...*
- *Caring, not rushed in appointments.*

- *Respect for my intelligence, the research I do, my self motivation and actions I take to manage my illness. Kindness. Acceptance, no stigma. No judgements, no assumptions.*
- *I was able to google GP's in the area and find someone who specialised in women's health and had an interest with mental health. That is super important to me so having that information readily available made it a lot easier to know I was seeing someone who was interested in helping my condition.*
- *Listened. Gave me space to move at my own pace. Gave me choices. Did not judge. Made me feel safe. Seemed to genuinely care instead of wanting me in and out asap.*
- *Experience with my problems, non-judgemental, offered useful advice & perspective.*
- *This only applies to one psychologist and one holistic health practitioner- They didn't have a one size fits all approach. They didn't make assumptions. They could acknowledge context and complexity. They understood that my "thinking" or my "attitude" was not the main problem. They had a thorough understanding of both trauma and neurodivergence.*
- *Very warm and understanding and real. I was in a terrible state when I reached out for help and could very possibly have just committed suicide rather than deal with the ordeal of recovery. After two years of extreme trauma I desperately needed someone who was going to support and guide me and to feel safe with.*
- *The psychiatrist made it clear that she was "in it for the long haul". Given that I had chronic fears of self loathing, self doubt and fears of hurting others (including her), this was reassuring (even though it needed to be repeated hundreds of times over).*
- *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.*
- *He is highly empathic and can sense my mood changes. He responds well to my mental health needs most of the time.*
- *My psychologist is wonderful, & she's trained in Dialectical Behaviour Therapy - one of the therapy types recommended for my diagnosis, & I find working with her very helpful. My psychiatrist didn't force medication on me, nor did my GP, unlike previous ones, which I respect & value. They both allow me to actively take part in decisions about my mental healthcare.*
- *For 2 yrs I felt belittled minimized and my views were not validated until I decided to opt for private psychiatric care*
- *Well informed, patient centred care, good record keeping, encouraging - looking at overall well-being not seeing mental health as some isolated 'problem'. Bulk billed regular appointments.*
- *Was willing to work at my pace. I was very scared to begin recovery and instead of judging me for this, took the time to go in-depth about my condition and the treatment that was most likely to help. The first few months were about learning more about my feelings, how to recognise them,*

and what benefits I would receive from engaging in recovery rather than jumping straight into intense treatment with someone I didn't really know. I still felt challenged every session but I was comfortable in doing so. I always felt in control.

- At the private hospital the nurse doing my admission said to me "P..., you have been her before. We know that when you come in you work hard on your recovery. We believe you will be back on your feet soon, back at work and back to your life at home soon." I realised after this that she was holding the hope for me, which I did not feel at the time as I was filled with guilt and shame for not being able to maintain my wellness and becoming unwell again. I will never forget those words.
- I have struggled to connect with most service providers, and it is very difficult and time consuming to organise more appropriate supports.
- The first service I used I disengaged from due to the professional being harmful and medically negligent. However the service I use now, has a psychiatrist who is very warm and a sense of humour which helps me stay engaged.
- Didn't care. Didn't listen

Are there particular qualities of the health professional that made you / the person you support feel uncomfortable and want to disengage?

When asked if they were particular qualities of the health professional that made them feel uncomfortable and want to disengage, the following comments were provided by **consumers**:

- The psychologist didn't/doesn't seem to understand my situation at all. Couldn't even empathise or grasp how difficult things had been or still were/are. You can never get an appointment when you need one and end up waiting at least a month between visits. And, if you are ever in crisis, they are completely unable to help; they won't even try. He is also extremely expensive and it feels like money is all they care about. If I can't pay immediately, they hound me until I do. Calling multiple times a day, leaving messages on my voicemail and sending multiple texts and emails that are aggressive and demanding. This is despite attending their clinic for years and NEVER ONCE not paying.
- Rude, don't call back, judgemental, make assumptions, don't take me and my problem seriously.
- I'm worried about judgement. I'm worried about not having anything to say. It's so much money to see a psychologist. I've had a bad experience in the past with a psychologist, who didn't listen to me and instead suggested a billion strategies.
- The way I am talked about in documents, eg. including irrelevant medical information in GP written referrals to specialists. When a psychiatrist agreed to write a letter of support, then did not, I felt cheated. I felt my own opinion of my mental health was not listened to and I was at the mercy of the opinion of a psychiatrist or a GP. I felt I was never asked to complete any formal paperwork or proper

assessments of my mental health and none were offered to me, which made me feel the assessment was unprofessional and biased against me and that I was not included in my own health care treatment. When no goals were made about my mental health care with the medical professionals I engaged and I was required to have continuous monthly appointments with a psychiatrist for no reason. When my physical symptoms of a medical condition were called "all in my mind" by a GP.

- Being called by one of the labels I have. I have dissociative disorders, major depression, PTSD and bpd. One worker only ever refers to me as 'a bpd' and that 'bpd's only need...' or 'bpd's choose to stay bpd's because its easier' etc.
- From doctor hopping, any health professional that was too abrupt or rushed or not skilled in working with mental health was more damaging than helpful. Hospitals are awful when they're over capacity.
- Using words like "bad", "complex" and "severe" to describe my mental health problems when I didn't use them myself. An emphasis on the experiences I was divulging, not their perceived severity of them would have been more helpful. Also their avoidance of diagnostic language, I get that it's stigmatising but using them as a framework to understand myself is helpful to me.
 - » This is in regard to most psychologists and public system
 - » They assumed they knew what was going on
 - » They underestimated my distress
 - » They underestimated the trauma of past experiences of invalidation in the mental health system
 - » They never asked me why I was suicidal or the feelings behind it
 - » Their only response was to give me olanzapine and send me home, or more olanzapine and then ignore me in hospital
 - » They misinterpreted dissociation as me being "calm"
- They referred me to beyond now app when my life has basically been a rigorous suicide prevention plan for two years and they didn't seem to understand that presenting to them WAS the last thing on my plan.
- They don't listen; they don't believe previous diagnoses, they're too quick to hand out dangerous medication that isn't helpful.
- Professional services appear to resist providing support for Borderline Personality Disorder diagnosis.
- I have disengaged with services that I am uncomfortable with as a matter of self-preservation and protection. This has included extricating myself from compulsory admissions as soon as possible, and cutting all ties with the public mental health system outpatient "care", including case managers etc. The services that I disengaged with were routinely infantilising, condescending, dehumanising and traumatic.
- We would end a session with plans for the next but these plans were always forgotten when I arrived at my next session. I understood that they can not just remember everything they say to each patient but it felt like they

weren't taking notes and/or reviewing them. The sessions lost their flow and I feel as though I've lost momentum. I feel like I'm having to tackle things on my own a lot more. This has led to me pulling away from sessions more and taking larger gaps between appointments.

When asked if they were particular qualities of the health professional that made the person they support feel uncomfortable and want to disengage, the following comments were provided by **carers**:

- They were frightened and didn't trust anyone.
- Constantly going over the same process each week. Like they just need to tick boxes.
- Mum has been placed under involuntary treatment and because of this she now refuses to call Lifeline and she is frightened of police officers.
- Mental Health and ER staff were highly invalidating, judgemental, unprofessional, uncaring, unethical and ALWAYS made him and I feel worse. They took away our hope he could get better.
- My daughter became angry because I had told the team everything I know.
- The provider kept delving into past childhood trauma for details, did not provide coping mechanisms, did not assist with day to day difficulties, made him feel like family was the problem.

2.4 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.

If support was not provided for long enough, who made the decision to end support?

When asked who made the decision to end support when it was not provided for the length of time they felt they needed it, the following comments were provided by **consumers**:

- A mixture. No helpful transitions; either they disappear, or forget boundaries and hang on too long (9years) until burnt out. Some actively block access (public) to anyone deemed "unfixable" (from my PMR). I didn't have the alternative experience or choice before I got my AD but since getting him I've never been back to hospital or any mental health public service. Turns out my chronic depression came from being abused for decades, traumatised and misdiagnosed and stigmatised because of the labels my official documentation branded me with. I'm still in a terrible situation; sever psychosocial disability, cognitive and other functional issues; but for the first time in my life I'm not clinically depressed.
- There are no other options, there are lengthy wait lists, you have to retell your trauma over and over again and you get know where. It is traumatic time consuming and costly to engage a private service
- Most times it's the health service, I have a very clear start date to my injury (PTSD) and I'm astounded at the differing medical treatment between physical and psychological conditions - I think the public health systems and support networks are just overwhelmed so they try to get you off the books as soon as possible - I don't think anyone really understands the costs of having mental health issues (most people I know require top level health care just for hospital/ Med changes which are dangerous to do on your own... but that combined with extreme medication costs etc is just a different type of poverty.
- Always been them. Psychologists leaving and discharge from acute care
- Most services have a limit of 8 sessions followed by a review. I've been fortunate to be engaged with a local service for 9 months, until I was sexually assaulted and the service referred me to a specialist service for victims as this was out of the expertise as a Women's Health Service.
- Ended before I was ready because life got in the way, program ended, 10 sessions ended and cost was prohibitive.
- Mental health care plans are a joke!!! For people who are experiencing depression and anxiety due to trauma 10 session gets to your trauma and then leaves you to manage yourself. I am fortunate enough to have had the inner resources to cope but I know there are many, many more out there who this is not good enough!
- Free service provisions provided by the Government ran out. I feel these should be extended in a permanent

manner, with anywhere between an x8 to x10 sessions. Then slowly decrease the time between sessions or if there is no improvement, to be referred to another service provider. With an additional extension.

When asked who made the decision to end support when it was not provided for the length of time they felt it was needed, the following comments were provided by **carers**:

- *Early on in our journey we had MH try to pass us on to disability services. It was not till several years later that we were able through our persistence to get our person into MH rehabilitation for 18 months that things started to improve. Everything that has been achieved is in large part due to our persistence, advocacy, knowledge, experience and skills and getting the right people in MH and provider organisations and ultimately a good NDIS plan.*
- *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 through phone call risk assessments 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.*
- *GPs always seem to be on a clock and it’s always clear that others are in the waiting room waiting so you tend to sit on the edge of the seat expecting it to be short. Thinking of previous private psychiatrists that he has seen over the years, the level of support was always according to the psychiatrist’s routine and the model. The ‘living with’ support needs were ultimately in the vastness of hours, days and weeks between appointments.*
- *PHAMS program ceased, no similar accessible mh recovery support program. Consumer deemed ineligible twice for ndis through quite a taxing and arduous process that detrimentally affected consumer’s mental health.*
- *Because he didn’t always answer their phone, the mh team decided to discharge him.*
- *Feel like it was just too hard to find an ongoing clinician/ support worker within the organisation.*
- *He felt he was not progressing and in fact his condition worsened.*
- *As a family we made the decision to disengage with the public mental health service as they were only resources to support our daughter in her eating disorder and refuse to diagnose and provide appropriate support for her personality disorder that had been differentially diagnosed 12months prior. They would not discuss her diagnosis with her, and it was frustrating to engage in the service that was not providing the right support - bordering on negligent - due to the professional stigma around BPD.*
- *Another issue has been the introduction of the NDIS, they don’t understand how it works and think if a person gets NDIS funding they automatically get funding for mental health - which is not the case and the NDIS try to force people on to the Medicare plans despite gap fees people can’t afford, etc.*

- *The psychiatrist support just got too routine like they ran out of new ideas and interest and stopped expecting that anything would change or be better than what it was. Felt like being in a holding pattern and getting to the limits of what that doctor had to offer. So felt a change might offer a new perspective.*

2.5 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.

Is disengagement (stopping) use of mental health services an issue?

When asked if disengagement from mental health services was an issue, the following comments were provided by **consumers**:

- *I guess it must be if people can't afford it but need it. That's what I'm scared of, luckily and nicely my parents are still paying for mine as I'm still yet to get a job of my own. But when I do get my own income I'm scared I may struggle to continue to afford my psychologist I've seen for the last 5 years and still need fortnightly.*
- *People are stigmatised against by health professionals. They are not listened to. They are not empowered by the services. They have no choices in who they interact with if they are limited to the public service.*
- *From my experiences with other people with mental illness, some of my friends just want to get off the meds and some of them have done that, only to fall in a very, very big hole without the doctor's consent. People with mental illness need support, BUT, if they are not comfortable with the support that they are getting from drs, etc, I feel that they give up as they are afraid to find another dr, etc.*
- *You end up spiralling and the worse you feel the less able you are to get help.*
- *The mental health service in Australia is an absolute beast to navigate. The referral pathways and eligibility criteria are very unclear and leave a lot of people ineligible for services they need. The amount of effort it takes to self-advocate for appropriate care is quite frankly too much for many people experiencing mental health concerns. There is insufficient outreach, a serious lack of affordable public options, and leaves the burden of system navigation*

solely on the health consumer. The workforce itself is also undersized and under resourced, leading to long wait times and inadequate care provision.

- *It's hard to ask for help and keep asking for help. Being shoved in the 'too hard' basket is heartbreaking.*
- *It takes time to build a rapport. Sometimes the fit isn't right.*
- *I am fortunate to be in a position to be able to afford the significant gap payment in the Medicare-subsidised psychology sessions (Mental Health Plan) and to afford private hospital insurance, allowing me access to a private psychiatric hospital. But there are many who cannot and their mental health suffers because of this. The 10 subsidised sessions are not sufficient for people with serious MH issues, nor is the size of the subsidy. In my case the gap payment is around \$150 (after the Medicare subsidy) for a single psychology session. Most people I know cannot afford that in the short term, let alone the long term. So they do not seek, or disengage with, treatment too early and their MH suffers. In addition, I have heard of scenarios where someone is allocated some care through a government funded organisation (such as headspace) who bulk-bill using the Mental Health Plan, and have either had a revolving door of counsellors, or get stuck with one who they cannot engage with. Both of these scenarios can cause these consumers to disengage. Living with MH issues is tough, and many consumers do not have the courage or the resources to stand up and say "hey, this is not working for me".*
- *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. I think people are often too proud and they think they are a lesser person taking meds. Well, let me say, those that stay the course are the strong, responsible and respectful of others.*
- *I would say in the public system, those with a trauma history are often discharged before they are ready, and others are forced to stay on seeing services longer than they need, and thus become institutionalized. And if you try to disengage, you often get an treatment order put on you. Whereas in the private sector it's easier to disengage because you're a voluntary patient and paying for the service. So it can happen at a higher rate.*
- *People in need of mental health support often reach out more in hope than anything else. If the process doesn't work particularly well for any reason, they can quickly become disillusioned and give up. Not logical but it is what it is, given the consumers state of mind.*
- *Mental health services are aimed at creating dependency on them, rather than enabling people to fully recover. People can feel safe within those services and become unwilling to step out of their comfort zone to disengage with them once they are well. There is barely any focus on full recovery from mental illness because psychiatry is not*

set up to allow this. Psychiatry says mental illness is for life. People who disengage after a diagnosis are seen as 'crazy' and labelled non compliant by the system.

- A bad experience with a mental health service scars you and leaves you with the baggage and distrust of the system. I no longer want anything to do with the public mental health system because it is broken and there are no avenues for reform.
- Partly because no one is listening to us. Partly because they see us as a production line with too many people and not enough staff. Some illnesses are too much trouble so they just brush them off as having to deal with them in the community. Refusal to refer in to programs that could help because a person / illness is too much trouble or too hard to deal with can be a problem.
- Facilities that are undignified and feel unsafe. ie broken chairs, old, dilapidated and ad hoc (not designed for purpose) buildings and facilities. Fatigue from seeing a different psychiatrist every time - retelling your story, no continuity in treatment approach, availability of an appointment in the timeframe that you need it, having appointments cancelled and rescheduled makes you feel hopeless. Location of the consultation rooms next door to the secure mental health ward. The psychiatrists don't bother to read your notes properly, they say they will contact my GP and psych with letter but the letters never arrive and I have to spend weeks chasing them down.
- There is frequently a large gap fee charged for mental health services and no opportunity for getting to know the clinician beforehand. The combination of mismatched core values/treatment styles, lack of affordability, and lack of appointment availability can make it difficult for even the most persistent people, who want to engage with mental health services, to access ongoing support. I imagine that for people who experience symptoms such as paranoia, have a less than positive view of psychology, or whose support network is prohibitive of them accessing support for mental health, these barriers could be incredibly difficult to overcome. After discussion with a male family member, he also mentioned that he thought he wanted to see a psychologist about feeling anxious, but that it would effect his application for income protection insurance. So I think there are still practical hurdles to overcome other than the direct social stigma associated with accessing mental health services.
- Patients are overwhelmed and can't take on board what is being explained to them. They can't grasp how their treatment plan will help them. They feel as though they aren't making any improvement as they lack understanding that recovering from a mental illness takes time. There is no quick magic cure.
- I think mental health support is pretty sporadic and uncoordinated and especially if you have not much money, which many people with severe mental health issues struggle with, then you are stuck in so many gaps, especially since the NDIS when services have become even more fragmented for people who don't have the people with lawyer skills to

help them navigate such a complex system. I know so many people and carers who have contacted their local mental health services for support and just get no help at all, or only really crisis emergency care involving police just to spin back into the same cycle because no one is managing the long term health and care. It's very concerning.

- I think people need help and want to do the work to recover but the only approach available is to sit in a room and talk to someone for an hour a week and take ever increasing doses of drugs. I have found it extremely frustrating how often I have sat in a room with people telling me about things I already know are good for me (eg. Exercise, mindfulness, structure, sleep hygiene) when I am reaching out for help precisely when I can no longer function enough to do those things on my own. I think people disengage because the help is not helpful or appropriate to the need and sets us up to fail.
- Mental health in my opinion is usually a long-term treatment, I believe even 6 medicare sessions is not enough. Unless it was a temporary mental health issue, I don't believe stopping the use of mental health services is ideal.
- I think you need to maintain services so that you catch the dip before you cease functioning - by the time your attempting suicide it's a very long way back but there is no interim before you get to that stage - even if you have the ability to ring hotlines are often engaged or lengthy wait times - I have often wondered why there are not mental health hubs that are drop in centres attached to hospitals that act like a triage centre somewhere for you to go when you have nowhere to go.
- What do you mean by "engagement"? What is "disengagement"? Why do people disengage? In my experience, the coercive nature of the mental health system, its lack of individualised care, its dehumanisation of people, mean that people are traumatised and need to leave that system as soon as possible/practicable. I've had three compulsory admissions and in each, I was sexually harassed and physically assaulted, which reminded me of being raped. Leaving that system was not a question of "disengaging" - it was a matter of survival. I've sought treatment that is evidence based and safe. The only place to access that has been some programs in some private hospitals, and private psychiatrists. It's been hard to find and hard to maintain because of the prohibitive cost, as mentioned, \$7,000 out of pocket per year for psychotherapy, plus top level private health insurance, plus medication.
- Yes, because many people disengage due to not having their views, beliefs and holistic needs understood or catered to and can't bear to continue service use. However, they still need mental health support and often end up needing it more after disengagement but are too disillusioned to return to mental health services. Our mental health system cannot possibly provide personal recovery as the national framework guides because it doesn't understand true personal recovery. Also, because the system is not designed to provide it by the very nature of only providing one offering - the biomedical model. Bio-psychiatry is highly unscientific but has managed to legitimize itself though a monopolizing

effect -sheer dominance. Some other international models don't use this approach and have much better results. We just do what we've always done which isn't a good enough reason to continue. It is not working for many.

- Firstly, the services for those with bpd are woefully inadequate. Hosp staff do not understand the condition, behaviour or complexities of the condition. No real treatment is offered. Hospitals are for triage. Long wait lists. Staff stigmatise and retraumatise patients. Patients are blamed. People would prefer to deal with the disorder on their own than go to hospital. There are no alternatives in the community for long term treatment. Secondly, those with bpd have a high drop out rate from services and treatment because they are highly traumatised, they have little or no supports, the care is not wrap-around or holistic, their other basic needs are not taken care off, their issues are complex, their homes are toxic, they have no carer, addiction compounds the condition. They are unable to regulate their emotions and must leave, they are not understood or treated with respect. They are seen as manipulative. They are judged harshly and blamed for their condition. Their childhood trauma of abuse, neglect, abandonment, etc, is often recreated within a hospital setting, they have no coping skills, they are unable to know or articulate what is going on for them, their trauma, fear and frustration manifests as aggression when fight/flight us activated. I could go on.
- People who stop using a service do so for several reasons. These include a) their health is not improving; b) they cannot afford treatment or medication; c) they do not feel their service provider relates well to them, and they may even feel stigmatised; d) the number of funded treatments available are too few and too widely spaced; e) they may feel shamed by family and friends and self-stigmatisation.
- Many people are not given the time. Clinicians are very busy in community mental health services. Some are supporting 30-40 people - a recipe for a coroners court. Efficient and effective ratios of no more than 15 to one clinician ought to be implemented across all community mental health services. People need time, genuine care and support; guidance not orders; a balance between duty of care and dignity of risk. People need information to help them make decisions. We need a well coordinated team where a single person (decided by the person living with mental health issues) can ensure all service providers are aware of changes and plans; particularly around medications. We should not have to wait for a good pharmacist to pick up that there are interactions between medications. People need to have a true recovery plan guiding their decision making. Peer support workers are essential to promote the recovery space and assist people to gather information, encourage and support their empowerment. Peer support workers are not replacement for care coordinators and are best not placed within clinical teams where they are supporting a "case-load." This is not peer work. In Australia we need to return to the true values of peer work.
- Disengaging with a service leaves wounds unhealed, questions unanswered, relationships ruptured - the same

thing that contributes to the interpersonal trauma that caused my disorders. It then adds further anxiety about engaging with another service due to the fear of further ruptures. Which increases hopelessness, disenchantment, isolation, and helplessness etc. It's very damaging when the engagement wasn't positive or ultimately helpful.

- I think people don't get the support they need initially and are reluctant to seek support elsewhere.

When asked if disengagement from mental health services was an issue, the following comments were provided by **carers**:

- The people of mh services are not friendly, don't seem to care much, and don't help that much.
- They need follow up support. Often, they have nowhere to go after hospital. It's about supporting them back into the community.
- People with complex issues whether it is trauma and mental health, dual disabilities, comorbidities, and a combination of all or even just complex trauma will be exited from services because they are just too hard.
- In particular for the public health sector, a lack of continuity of health service providers, eg seeing a different clinician/ doctor at appointments. A shortage of services, long waiting times for assessment. People not believing they need medication or treatment, lack of accessibility to services especially in the community, lack of affordability. Unwillingness to involve carer/support people in the health care plans. Carers not being listened to, especially if there's lack of insight of having a mental illness (also no support from family).
- Communicating with health system is difficult. If my husband did not have family advocating for him, he would be living on the street.
- It's not that my mum "disengages". It's that the service fails to adequately engage her! They don't try hard enough to help her, and they treat her like a child or like she's just risk to be managed.
- The lack of relationship building does not allow trust to build. These people are in extreme distress, they need to trust those who will support them through recovery. I have heard comments re the constant change of doctor registrars etc and how disabling this is. They feel no-one really cares, which is probably true in a system that cannot provide regular constancy of staff.
- I know quite a few people who disengaged when they felt the person wasn't the right fit, or as soon as things got marginally better.
- Wait times, rude professionals, rescheduling of appointments are all contributors.
- I think people just want to feel they can trust that the person they seek help from will really listen and be able to help. Often, I think they are disappointed by what they then experience with service providers who seem more caught up in their own 'professionalism' in how they dress, speak, behave and ultimately treat the person as just another 'patient' in their day. It takes a lot for people to seek help.

It's a confusing and anxiety provoking experience to do so. So, I suspect a lot of people retreat and just try to manage and solve mental health problems themselves.

- The Public Mental Health System that pays lip service to "holistic health", and really is only interested in the "medical model" will never be a fully functioning, collaboratively working mental health model that sustains and nurtures healing.*
- Mum needs therapeutic support for her trauma history and the resulting mental health and AOD difficulties. Instead she just gets crisis intervention and risk management strategies but no proper meaningful engagement. She also gets labelled as "Drug and alcohol" but the AOD services also don't make an effort to meaningfully engage her or her family. She is frightened of detox and she has nobody supporting her through that journey. They take her mobile phone away and this also scares her, so she never goes through detox. There are also hardly any residential rehab facilities around, and she can't afford to pay for any anyway.*
- My daughter died by Suicide...2018, 6 weeks and 2 days after being discharged from Hospital where she had 2 referrals to the [community] Clinic, 1 was the Mental Health Clinic and the other one was Drug and Alcohol. I have done my own investigating and not 1 person from any of these services made contact with my daughter even though the hospital put her on a concoction of prescription medication.*

From your personal experience, what happens when you/the person you support disengages from a mental health service?

When asked when happens when you disengage from a mental health service, the following comments were provided by **consumers**:

- I can't speak for others, but for me I was able to self-manage for a decent amount of time, but when I was in crisis the crisis was made much worse by the fact that I didn't have a support network there and had to rely on emergency services/start relationships with new clinicians while experiencing intense distress.*
- May 1. fall into the criminal justice system 2. forget to the keep looking after themselves 3. not keep up with medication regime 4. physical health deteriorates 5. become homeless 6. get visits from the council re state of home environment 7. lose their jobs 8. relationships with family and friends deteriorates due to mental health failing*
- Personally, I just dealt with my feelings myself. I felt worse, because I believed no one could help me.*
- Get lost lose Hope. Carers who look after them become mental health people themselves as a result and snowballing affect. Professionals need to see the person as a human being not a diagnosis or consumer (hate thus label and term I am a person not a retail item).*
- Their health can deteriorate until it's a crisis. More preventable interventions could exist if mental health was funded and supported properly.*
- I know a lot of people who won't pick up private numbers - I think if there was a text service people might be more likely to continue- usually people continue to deteriorate and by that stage often they don't want to seek help (you only get so many attempts at it before people give up) I think carers& friends also needs lot more ability to be able to signal a service to check up on someone (without of course getting their medical info for example say X is a patient of the community they need some follow up because many people loose the ability to see when they need help - in my cases most end up dead or disappear (some resurface months later - I have been surprised that there is zero follow up from private hospitals - even if they referred back to community health.*
- At one end of the scale you might have a person who regresses/deteriorates significantly and they might engage in self-harm, suicide, become psychotic, undertake risky behaviours or generally become mentally unwell. They may also withdraw from other services they were engaged in. Some people may travel along rather well following disengagement from services, but then something triggers them and they have trouble finding supports.*
- They try to manage on their own. They try to ignore what is happening to them. They put a mask on every day when they are around family, friends or at school or work pretending to be "normal" or "happy". They live in fear that they will be found out and will lose their freedom ie: be put in Hospital, dismissed, judged. They feel guilty, ashamed, isolated, hopeless. They are exhausted from maintaining a facade. Sometimes it's just too much and they may self medicate or engage in risky or self harming behaviour.*
- It depends. Some peoples recovery is ongoing and they just need access to support when there is a relapse or triggers.*
- Mental illness is complex and it needs to be treated as such.*
- Majority of the time when a person is going through a crisis; they may not realise it.*
- One of the first things affected is self care. Attending an appointment with a professional is hardly priority for them during crisis.*
- Most people have anxiety leaving the house during periods of being unwell.*
- I think people feel a bit lost, without any support at all. It would help to taper off services slowly and offer a peer support program or occasional connection activities to help people stay supported.*
- Some just shrug and move on. Some try to re-engage with other more suitable services. Services should be listening actively to understand that not all mental health issues are the same and that they do not fully go away. Some service providers should see people in their home environments, people are often more comfortable in their own space. It would provide workers with an insight on how the person is coping and whether any additional services may need to be engaged.*
- I spiralled out of control. My world crashed down, I was helpless, suicidal, and utterly lost. It was traumatic.*

When asked when happens when the person you support disengages from a mental health service, the following comments were provided by **carers**:

- *They give up or they have family and friends who fight hard for them. But too often it's left up to family and friends and they have their own trauma from the experience.*
- *They lose hope and it puts them on a path of drugs and alcohol to numb the pain. Families go thru hell.*
- *They are isolated, their living environment and their mental health deteriorates, they suicide, they are lonely, vulnerable, their physical health also deteriorates, they disengage, and their quality of life is reduced considerably. There is more burden, ill-health and reduced quality of life for their families.*
- *Loss of hope, anger, disappointment, resistance to engage in the future, possible suicide / self-harm attempt.*
- *Self-medicate with alcohol and /or drugs. Keep in same patterns only getting more and more.*
- *serious. Take others down with them, especially their family and loved ones so that more people need help.*
- *I think many just try to find other places that meet their needs better. Some are successful, though it seems to take a long time and a lot of searching and loss of linkages with others in the process for some. For example, finding a GROW group after years of moving between services searching for acceptance and basic respect. Others likely become more reclusive and 'disappear' in the community a bit.*

Thinking about the health professional or service you/the person you support decided not to engage/continue with in the past, what was the primary reason for disengaging?

When asked what the primary reason for disengagement was in the past, the following comments were provided by **consumers**:

- *The above refers to my initial experiences with GPs, a dietician, and several psychiatrists. Often I felt judged, I had to repeat my story, people didn't believe what I was saying or take what I was saying seriously, my worries were dismissed or brushed aside, there were unprofessional actions such as the psychiatrist checking their phone during appointments or people entering the office during a consultation. The below answer refers to the initial experience with the health professionals too, before I went inpatient to a private psychiatric hospital and met my current psychologist there who I still see now.*
- *Being a minority community and peer groups not really accessible. I have large issues with transport and being able to afford to engage in activities.*
- *She didn't follow through with any of the notes she said she would be sending me after each session, she didn't hear me when I told her I was distressed and didn't want to participate in the task she set, she contradicted herself and left me feeling powerless.*

- *Feeling judgement and not comfortable were my main issues. But I felt more comfortable around others with lived experiences similar to my own. Here I felt better supported.*
- *An instance with a Psychiatrist made me feel the power imbalance and he didn't like me having a 'voice', no advocating for my daughter. I had to watch what I said, aware that he was the gatekeeper to the medication I desperately needed for her at that point of time.*
- *Generally it has been that the service was very goal focused, and that type of work feels invalidating and impersonal. I struggle to find trauma informed or focused therapies that are accessible, cost or eligibility wise, I have talked about my issues for many years, I have great insight, but as complex childhood trauma is the driver of my mental distress, many therapists are unsuitable for this work, or I cannot afford them, I do work, in a part-time capacity, so I am often not eligible for concession rates, but do not earn enough money to pay upfront fees and gaps, especially in an ongoing way.*
- *Felt they were not that invested in my care and only did the bare minimum. I had a lot of suggestions for my care but always felt I had to research these myself. Never tried to give any extra help.*
- *My mother tried to file a complaint about how my condition was worsening and it was being ignored. I was told I would get a special appointment with a senior psychologist. This was cancelled by them with no reason and no new date provided. I felt as though they really did not care about my recovery and that no one would listen to me.*

When asked what the primary reason for disengagement was in the past, the following comments were provided by **carers**:

- *A sense that things could not change. Loss of confidence in services/therapy.*
- *I have sat with mum in emergency departments and literally 3 different nurses and doctors will make her repeat her story. She becomes very agitated and frustrated by this as you can understand. Even myself as her carer will get frustrated! I don't know why people can't just read her notes. "Forgotten about" is a great way to describe it. I feel like the mental health and AOD systems just wish that my mum would go away. They want to forget her. Mum also doesn't even remember the names of services that are involved. She mixes them up all the time and has no idea who is her social worker, who is her support worker or where she is supposed to go. This is because the workers change constantly, and they use clinical systems language which makes no sense to mum.*
- *The peer support has been sought by us and it is not a group as the person does not cope with groups at the moment. They already felt stigmatised and justified by their lived experience and the public system just adds more to the impact of the trauma and stigma.*

2.6 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.

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

When asked if the health professional or service gave sufficient notice of their impending discharge, the following comments were provided by **carers**:

- *No formal discharge papers with a care plan, etc was ever given.*
- *Patient said don't contact her [the family/carer] so I don't get informed, although he lives in my house.*
- *We have experienced a MH service putting our person in a "doss" house run by a charity because they were unwell but not a "danger" to themselves or others, when they had no beds available in the psychiatric unit. Our person was subsequently discharged without our knowledge by the MH team. We were told of the discharge by the person running the facility, who was concerned and said that they were sick and tired of MH putting patients in their facility when they had no MH trained staff. We found our person wandering around in the middle of the city in his bare feet in the middle of winter very unwell. We have had other occasions when they were discharged too early without informing us or when we were informed they were being discharged when we were interstate for a few days and sent them home on their own to their empty accommodation with no support- we had to rush back. The hospitals tend to discharge people at weekends when the service providers and other services are not available.*
- *We will never access services again. It was a really negative experience. As the primary caregiver I felt judged and unsupported when my daughter wouldn't engage. The clinician was very nice at first but got quite nasty when my daughter wouldn't engage and she basically just said I needed to present to the hospital any time she is suicidal which isn't a solution as we did that and they discharge you immediately. After 3 years of battling to afford and find suitable services we will manage alone now as it is better than being involved with people who don't understand the reality of the experience. On a positive note we did access a private psychiatrist who commenced an antidepressant for my daughter, and this is a great outcome. It will now have to be managed by the GP.*

- *It was done at a regular catch up meeting with NO notice whatsoever.*
- *My child is 19 so I am not consulted ...I just pay the bill.*

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.

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 mental health?

When asked what would help people stay engaged with health professionals or services or return to a health professional or service to receive support for mental health, the following comments were provided by **consumers**:

- *This is a hard one. People in this country are becoming more and more lazy and expect society to do everything for them. They really should be putting their hands up when in need. Maybe governments could do advertising (TV- but very expensive and less and less relevant to young people) to educate people.*

- *Investment in time and people which cost money to actually visit people. Fund Medicare services so that GPs are rewarded for their extra effort to deal with patients who have mental health issues or include mental health as a skill set of practice nurses to follow up in the first instance.*
- *Call them and check up to make sure they're alive/okay and let their GP know it's happened! My psychiatrist didn't call to check I was alive after I disengaged even though I was high risk and mentioned suicidal ideation and a suicidal plan in my final appointment. It made me feel I was worthless and that I had been a waste of her time.*
- *I want my regular providers to contact me if they haven't heard from me in a while. Since I usually have a set frequency, they should be worried if I miss sessions. They think this is because I am well and don't require their services, when in fact the opposite is true.*
- *Provide the service that those people need. I.e. specialist support for their specific needs. Have options like a community group/peer support group. Group counselling etc. A day centre or service that people could drop in to for help (i think Victoria's new model seemed amazing).*
- *Value their input and engage in co design process.*
- *Offer services that fit with clients particular needs, provide open dialogue, give choices and options, show open-mindedness, consistent therapists, be transparent, offer alternative options (meditation, exercise programs, peer connection groups, art therapy etc).*
- *Do they have to? Some people may be better off not being in a mental health service given they are often retraumatizing.*
- *Have a hub for info, get pharmacies to have a greater caring role (most have to pick up meds frequently) maybe have a go check in system that's digital like a how have you been feeling type thing - having duty of care in ndis where people can fund and suggest new activities and train staff so they know about them.*
- *Gently and kindly. The best thing for me was to have regular visits from a social worker who had lived experience. They understood how difficult getting help could be, and acted as a dependable rock I could rely on for support. They helped me to co-ordinate the extra supports I required, and to liaise between the deterrent specialists. Patients who have disengaged need an empathetic, understanding SINGLE point of contact. Someone the buck stops at. To ensure continuity of support.*
- *Don't be so quick to close people, understand that patchy attendance is often a trauma/anxiety/depression response and let people know that they have time to get comfortable. Employee peer workers.*
- *Stop defunding funding models for different transient unreliable schemes. We don't need schemes, we need consistency, routine, reliable supports we can feel confident in.*

When asked what would help people stay engaged with health professionals or services or return to a health professional or service to receive support for mental health, the following comments were provided by **carers**:

- *It's the approach that is taken to the client, when the client is in a bad space, don't give up trying to contact them, keep phoning, or turn up at the house, Services give up because the caseworkers are overstretched, too many clients & not enough hours in the day.*
- *Peer support in hospital for all crisis situations 24 hours around the clock! Immediate follow up after a suicide attempt once left hospital. Immediate link in with services, 48-hour Max wait to receive support from the linked service.*
- *Consistency in services. Holistic approach connecting bio psycho and social dimensions. A therapeutic environment where safety is measured by the sense of security of people who use the service. Culturally responsive service that understands other visions of the world and hence other conceptions of mental illness Mental health professionals who speak English slowly, with no jargon and with a tolerant attitude toward who don't have English as a second language.*
- *Communication between service providers.*
- *Trust must be in place across the board. Carer, family, health teams have clearly delineated understandings and knowledge of where to go, what to do etc. Must be a sense of valuing of the consumer. Holistic care must be brought in- not just symptom treatment!*
- *Consult and discuss collaboratively with the person, their support people involved (family, friends, carers, advocates), support workers and community MH staff (managers, psychologist, psychiatrists) to make sure they have the whole picture. A variety/diverse of available entry points to the system to cater for everyone's diverse needs and methods of engagement and the situation they are in. Community hubs, walk in centres, outreach, GP practices with Mental Health nurses, digital, online.*
- *People would stay engaged if they felt respected and felt safe, felt they were being genuinely listened too, including their family, and perceived that workers believed in them too and were hopeful.*
- *Compassionate, non-judgemental, ethical care.*
- *Clear assessment of what worked or didn't work last engagement, changing course of treatment as per individual needs. Fitting service to consumer/family not the other way around.*
- *More choice in services, not all people fit into the service delivery model.*
- *Using peer workers to help build trust and be a bridge for people.*
- *Listen to complaints, respond to them Acknowledge errors and shortcomings. Ask "what can we do to work with you".*
- *Offer to meet them and listen to what they have to say about what support they need.*

- *Better afterhours crisis services in ED departments. Less judgement.*
- *There needs to be a bigger investment in community outreach services with regular quality follow-up and engagement.*
- *Promote a new 'face' to health care services. Advertise on mainstream media. Promote health care as really being caring, not only of your clients but of their staff. Get rid of bullies. They're everywhere, long term workers, who make good caring workers leave and make clients lives hell...Make it about all health. Why demarcate people at the neck? It makes no biological sense to separate mental health from general health.*
- *Longer-term and more inclusive case management in the community would allow for better development of trust and engagement. Readily available professional peer support - my loved ones got the most effective support from regular contact with casual peers, this needs to be included in every mental health service. More pervasive community services and awareness of these would also assist in reduction stigma, which is still a huge barrier for people accessing support.*
- *Contact them to reengage and be persistent, find things that they can relate too, ask them what their interests are, find something that has meaning for them and never ever ever give up until all options have been tried.*
- *This is a real hard one - get it right in the beginning.*

2.8 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.

If you / the person you support presented to an emergency department and were not admitted to hospital, please explain what happened after discharge?

For consumers who presented to an emergency department when in crisis, but were not admitted to hospital, we asked what happened after discharge. The following comments were provided by **consumers**:

- *Previous traumatic, judgemental, stigma-loaded, unhelpful experiences in public hospital EDs has caused me to avoid utilising them as a resource in a crisis. I often was discharged in a worse and more helpless/hopeless position than when I arrived. There was no follow up at all and no referral to other services. This then, in a crisis, leaves me unsupported because the private facilities and services I use do not have emergency facilities or services.*
- *I self-advocated and spoke to the Social Worker at my university who helped me sort out crisis MH support.*
- *Went home at 1.30 in the morning, using a taxi as I had arrived at the hospital by ambulance, and saw my psychiatrist at the arranged time of the next morning who promptly had me admitted to a private hospital mental health ward where I received treatment for the next three weeks.*
- *Yes 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.*
- *Given a taxi voucher after not being able to leave for 15 hrs - but the problem with that is for many ptsd patients the emergency department is very triggering do when your complexity exhausted you do t have the energy to seek help and fight that fight - as strange as it sounds when your senses are all elevated automatic and beeping, Fluoro lights etc just agitates you even more to get point where you can express yourself logically - having spaces that are sensory diverse would be a really good start - I also think tv should just be an essential in every public hospital without paying (& waiting 3 days for it to turn on).*
- *During the week leading up to my discharge from the private hospital i was encouraged to make an appointment with my GP and my psychologist. I was given my discharge letter. I was told a copy would be sent to my GP. She had not received it when I had my appointment the week after discharge. No discharge letter was sent to my community mental health worker even though this was discussed prior to discharge. I believe this could be coordinated much better. The private hospital made a follow up phone call to me in the following week to check in that i was doing ok and had kept my appointments i had made.*

- *Outpatient support is severely lacking. On my last discharge I finally got a case manager from Queensland health to do some follow-up, who was then able to refer me to RFQ. Should have been referred to them years ago. The barriers in place are outrageous.*
- *On one occasion of sitting in the ED chairs inside the unit (these chairs are meant to be for family) for 8 hours with no nurse checking in on me, when I felt safe I exited and told the nurse at the front desk that I was leaving. She said fine (as is Who care about you anyway). About an hour later a nurse called me when I was in bed flustered as he went to speak to me, after 9hrs of not talking to me, and accused me of doing the wrong thing by leaving. I told him that the front desk nurse said that it was fine. This made me feel so bad as if I was a criminal for leaving a totally unsupportive environment. He was so rude, he just told me off, and he made no attempt to be kind and wish me well at all. I had managed my way through another suicidal episode all by myself, and I was made to feel like a criminal for it. I will still go back to ED as there is no where else to go. And I will leave when I am ready, with no support at all. How poor is the state of ED's. Very.*

For families/carers who support a consumer that has presented to an emergency department when in crisis, but were not admitted to hospital, we asked what happened after discharge. The following comments were provided by **carers**:

- *Attempted suicide.*
- *Went home to become sicker and readmitted as involuntary patient.*
- *Left with no assistance at all. Ended back at another public hospital where was admitted and tied up!*
- *Discharged from hospital in psychotic state with no follow up. Person proceeded with suicide plan. Person taken back to A&D through MH Line and advocated for emergency treatment. Support person did not leave their side until medical treatment was administered and a bed became available.*
- *However, the community team didn't make contact. If I hadn't contacted them to ask if/when they were coming to visit him to provide the follow-up assessment and PRN meds the following day (as per plan from ED staff), then he'd probably still be waiting. Communication between the hospital and community team seems to be very hit and miss, delayed and confusing. It left us feeling quite at risk too.*
- *They were evicted from their accommodation and lived in a motel for a while.*
- *They were sent home, their carer told to be on 24-hour suicide watch - told to take things away from the person and that was it.*

2.9 Services for mental health 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.

What mental health services would you / the person you support like to access at the moment but can't?

When asked what mental health services consumers would like to access at the moment but can't, the following comments were provided by **consumers**:

- *I am lucky because my parents pay for my private health insurance and medication, so I have access to everything I need. But it would be beneficial for people if there were more public inpatient psychiatric hospital options that are therapy based, not traumatic, and can allow for a month's stay, not only 24/48 hours.*
- *Literally anything. I cannot currently access any support at the moment.*
- *It's not that I would like to access more services, I'd more prefer that my current services were more integrated. I see six different clinicians through five different service providers, and I lose so much time and energy to case coordination that it's hard to feel like I'm making any progress.*
- *I'm paying for the support I need and the financial burden is profound - would appreciate:*
 - » *\$7,000 annually to pay the medicare out of pocket costs to see my therapist and general psychiatrist*
 - » *\$1,200 annually to pay for medication*
 - » *\$2,700 annually to pay for top level private health cover with decent private hospitals - oh wait, federal govt could stop subsidising private health cover and actually create a decent, safe, effective, non-traumatising public mental health system*
- *Wellness drop in Centres - Authentic Recovery Model Framework. Free of and no attached to Mental Health Services - which are toxic.*
- *A Mental Wellbeing Hub, where there is information on relapse, recovery, ongoing management of mental health, and education centre for everyone. Not just for people who are in the system. As a preventative method to educate people on getting well, and staying well.*

- *Peer Work, but an external group/connection that is not linked with clinical mental health services. An independent peer worker org would be fabulous. Costings to be supported by local or state government. Like Brook Red in Brisbane. Peer run, peer lead. Which could provided access to all.*
- *Regular peer conversations, peer contact, opportunities to learn about mental health etc. I am wondering where these are offered outside of navigating the mental health system and being put on wait lists for an agency. If a person is unwell, and something gets too hard, we give up. Things have to be easy when we are fatigued and have little energy left to self-advocate. We want to feel as though the support person "gets us".*
- *Headspace... but realistically I would prefer if there was a better database for HOW to seek support, HOW to find a health professional suited to you. Even if that means more telehealth options so that the right professional is available. The issue I have at the moment is the town I've moved to only has one psychology clinic, and unfortunately for me this is where my fiance practice's so it would be a conflict of interest for me to see any of the other psychologists. But then it's hard for me to find someone who does telehealth that I would be comfortable speaking with as there isn't a lot of information available on who these professionals are, what their interests are, what their age is etc. to make it more comfortable for me to choose who I speak to if that makes sense.*
- *A service in between psychology & public health/hospital. peer group.*
- *Neuro feedback. Group therapy.*
- *Short term residential crisis care (like the Maytree in the UK).*
- *Medium to long term holistic residential programs that involve meaningful work.*
- *Social enterprises and opportunities to work.*
- *I miss social support. Since NDIS has come in all the social supports have folded up. We need some community social support groups back again under community health. We used to have them - a games room where patients could go in and quietly play a card game or board game. Or even just talk. We need to connect. We don't have anything anymore. We need a hub that is not expensive. Those that need to be funded by NDIS are not doing well - they are struggling due to low numbers, because of distance, because some participants may not have the funds or they may not know about the group. The groups don't run for long so it's not worth our while to attend. I used to go to a hub house for the day anytime of the week. It had activities, a chook pen and vegetable patch. People attended every day - friendships were formed. We connected - we had a community. It's all gone. QLD Health pulled it down and in its place built a Step Down Step Up Building (I think that's what it's called). All my friends who used to attend these places are now lost souls - lonely and mentally worse off.*
- *Intentional peer communities.*
- *Support to DO things.*

When asked what mental health services the person they support would like to access at the moment but can't, the following comments were provided by **carers**:

- *Social supports to assist isolation. Community supports outside of a mh team venue (ie building) could be meet for coffee, or walk, or meet in their own home if it is safe. Some of the things that people in our community do and don't think about, as it is normal interactions.*
- *Exercise groups for free, with people their own age, hobbies, maybe fishing, hiking, reading groups, art groups, that don't cost money.*
- *Integrate then in engaging meaningful friendships groups to stop isolation and build social skills.*
- *Psychologist with a regular and consistent person at no cost.*
- *Life coaching/mentoring/peer support. Drop-in centre geared to their needs and available every day.*
- *At times it is respite. Things can become so overwhelming at home and people need a place to feel safe, protected and cared for. Some people don't want to burden family/carers with their ongoing state of un-wellness. Some people may want to get away from Carers/family if things are difficult. For some it may just be a bed for a few nights. For others it may be a place to sit and talk to someone.*
- *Need more group supports in regional areas and more qualified clinicians in regional areas also.*
- *GP able to request urgent hospital admission to specialised unit.*



Lived Experience
A U S T R A L I A

www.LivedExperienceAustralia.com.au