ACT
Mental Health
Consumer Network

ACCESS DENIED:

A consumer-led study into barriers to accessing mental health services in the ACT.

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We acknowledge that Aboriginal and Torries Strait Islander lands were stolen and that sovereignty was never ceded. We respect the continuing cultures of Aboriginal and Torres Strait Islander peoples as well as the ongoing contributions they make to the communities and lands of the ACT and surrounding regions.

We also wish to recognise people with mental health illness whose resilience and work contributes to creating a better mental health system for the Australian Capital Territory (ACT) and a more compassionate society for all.

ACCESS DENIED: A consumer-led study into barriers to accessing mental health services in the ACT (the Report) is the final report of the *Barriers to Access Research Project* (the project), representing the joint efforts of staff and volunteers of the ACT Mental Health Consumer Network Inc. (the Network), its membership and the wider mental health consumer community in the ACT.

Every person who participated in the project was vital to both its success and the resulting quality of this Report. It is thanks to their work, time and considerations that this Report is in your hands today.

The Network would also like to thank the ActewAGL Community Grants Program for funding the project. We also wish to express our gratitude to ACACIA: The ACT Consumer and Carer Mental Health Research Unit at the Australian National University for their advice and contributions throughout the life of the project.

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103 confidential consumer participants

Contents

Glossary

There are several phrases and acronyms used throughout the Report. We have used several contraction-phrases to improve readability. Where relevant, these phrases will be qualified. For example, where it is necessary to refer to Australia's mental health system as a whole, it will be described as 'the national mental health system'. Likewise, phrases such as 'the barriers to accessing mental health services in the ACT mental health system' are written in the contracted form of 'the barriers to services in the system'.

barriers	–	barriers to access
consumers	–	people with lived experience of mental illness
programs	–	mental health programs that may be offered by one or more services
services	–	mental health services
the focus groups	–	Any or all of three rounds of consumer focus groups undertaken for the Barriers to Access Research Project
the Network	–	the ACT Mental Health Consumer Network Inc.
the participants	–	Consumers who participants in the project
the/this Report	–	*ACCESS DENIED: A consumer-led study into barriers to accessing mental health services in the ACT*
the survey	–	the Network's 2024 Consumer Survey
the system	–	the ACT mental health system

Executive Summary

ACCESS DENIED: A consumer-led study into barriers to accessing mental health services in the ACT (the Report) is a resource for every person who holds an interest in improving the ACT mental health system (the system). People with lived experience of mental illness (consumers) will find the voices their peers identifying and addressing the issues that affect consumers' ability to access mental health services (services). Community service leaders and workers will find detailed discussion of the issues and dynamics of consumer engagement with the system that affects the communities they serve. Policy practitioners will find consumer perspectives as well as discussions that highlight linkages between Commonwealth policy pillars and the experiences of consumers. Lastly, mental health professionals and scholars will find primary material, current secondary sources and conceptual discussion by which to better understand consumer experiences of the barriers to access (barriers) in the system.

Throughout 2022 and early 2023, consumers who engaged with the ACT Mental Health Consumer Network (the Network) consistently described experiences where accessing services was a slow and burdensome process that did not reliably lead to effective care and positive outcomes. In mid-2023, the Network successfully applied for funding through the ActewAGL Community Grant Program to investigate the barriers facing consumers. The Network wanted to understand the nature of the barriers that consumers were encountering, learn about the consequences that consumers were experiencing, and what consumers wanted to see changed to address these barriers.

To achieve these goals, the Network developed the *Barriers to Access Research Project* (the project) and implemented a research plan structured around three rounds of consumer focus groups (the focus groups). The project was designed so that participants directed the focus of the investigation by identifying the barriers that the project examined. The focus groups involved 103 participants attending 18 sessions over the span of six months, resulting in over 36 hours of direct discussions. Participant feedback from these focus groups was also used to redesign the Network's biannual mental health survey. The redesigned survey comprised the second major component of the project and it was made available for public response between April and May 2024 as the *Mental Health Network Consumer Survey 2024* (the survey). Results from this survey will be presented and discussed in a future study. This Report was produced via analysis of the focus group transcripts alongside review of publicly accessible reports and academic literature.

The outcomes of this investigation should be read in their context, that is, as findings produced from and about the lived experiences of consumers accessing services in the ACT. This being noted, the Report contains three sets of findings:

1. The Report provides conceptual insight into the nature and dynamics of barriers in the ACT. Specifically, participant feedback describes a complex relationship between material and holistic barriers that have manifold and compounding consequences for consumers who encounter them.
2. The Report presents and analyses the reported lived experience of consumers accessing the system between 2022 and 2024. Here, the majority of participants described their experiences in negative terms and described the system as opaque, expensive and exhausting.
3. The Report presents participant's recommendations and proposals for improving the system. These have been summarised in the next section.

At the heart of this Report is the desire for the ACT to have a system that supports and facilitates consumers to access services, rather than one that discourages and disincentivises engagement. Presently, participant feedback received by the Network describes the ACT system as one that penalises consumers with the fewest means and who face the steepest challenges. The causes of this situation are multifaceted, but meaningful changes can be made at the Territory-level.

Since the conclusion of the project in mid-2024, little has changed that would meaningfully alter this Reports' findings. However, the re-elected Labor government has pledged to increase investment in the public health system with additional targeted investments for mental health. This includes reinstating mental health care plans that provide consumers with up to twenty subsidised psychology sessions per year as well as funding additional training positions for the mental health workforce (Cockburn, 8 April 2025). These proposed investments are welcome and, should they be upheld, consumers in the ACT will benefit from them.

Nevertheless, it remains the case that more must be done to address the social determinants of poor mental health and mental illness (WHO, 2014; Productivity Commission, 2020; Guha, 12 April 2025). Housing insecurity and economic marginalisation continue to be serious problems in Australia (ACOSS, 2024). Consequently, if our socio-economic system creates conditions wherein people are unable to meet their basic needs, then the deprivations that these conditions cause will continue to produce an overflow of malaise and maladies that the system will invariably struggle to meet. It is therefore the Network's hope that this Report can serve as a spur to public action and help to bring about a better system for all.

Recommendations

For ease of reference, we have summarised the specific recommendations made by participants for improving the system. There are many overlaps between recommendations and the issues they aim to address. We have organised these recommendations in relation to each of the overarching categories of barriers for which participants made these recommendations. The categories and accounts of these barriers were developed through participant feedback. As such, these recommendations speak directly to the problems that participants themselves described encountering and experiencing. Each of these recommendations corresponds with specific feedback that is presented in this Report. As such, while these recommendations span a wide range of policy spaces and levels of governance, they are also a clear presentation of participants' views on how to improve the system.

Improving the holistic accessibility of services

Recommendations for improving the holistic accessibility of services address barriers that arise within the process of providing services. This involves key facets of service provision, namely, the quality of care, interpersonal interaction and the navigability of the system.

1. Peer-led and lived-experience services and programs should be developed, trialled and implemented within the system. Participants specifically recommended the development of the following kinds of services and programs:
    a. A peer role within hospital emergency departments for supporting consumers who present for mental health concerns.
    b. A peer-led support service that assists consumers will navigating the system, managing information and facilitating warm-referrals.
    c. A peer-led advocacy service that provides consumers with in-person assistance, mental health consumer rights information and service-accountability support.
2. Existing peer-led and lived-experience community organisations, services, programs and groups should be identified, engaged and proactively supported by the ACT Health Directorate. Participants specifically recommended:
    a. Identifying and supporting established peer-led community groups that provide social, specialised, and non-clinical supports in the Canberra community.

3. The standards of mental health care service provision should be improved by auditing service providers for safe mental health practice, upskilling existing health workers and providing more specialised training for future health workers.
    a. Existing and future front-line mental health care workers should have better organisational support and training to practice safe and empathetic mental health care.

Improving the availability of services

Recommendations for improving the availability of services addresses material barriers that arise as a result of there being no service providers in an area or of services that have insufficient capacity to meet demand in their areas of operation. Participant recommendations here address both Commonwealth and Territory level barriers, the list is therefore arranged with reference to these levels.

Commonwealth

1. Access to the National Disability Insurance Scheme (NDIS) should be expanded to provide coverage for psycho-social disabilities, especially for consumers who require access to ongoing services and supports.
2. The number of subsidised sessions provided by Mental Health Care Plans under the *Better Access Initiative* (BAI) should return to twenty sessions per-year.

Territory

1. Community spaces, supports and events that facilitate positive social interactions and engagement through free activities, exercise and learning should be developed.
2. Piloting and expanding the range of non-traditional services and programs that offer clinical as well as non-clinical options.
3. The ACT Health Directorate should develop a means by which to map and maintain up to date information about services that is available to service providers, community organisations and consumers.

Improving the affordability of services

Recommendations for improving the affordability of services addresses material that arise from the market-based organisation of both our national health care system specifically and society generally. Participant recommendations here address both Commonwealth and Territory level barriers, the list is therefore arranged with reference to these levels.

Commonwealth & Territory

1. Both the Commonwealth and Territory governments should greatly increase public investment in services, supports and workforce.
2. Both the Commonwealth and Territory governments should develop proactive strategies for addressing the social determinants of mental illness: housing insecurity, economic marginalisation and social exclusion.

Commonwealth

1. The Commonwealth government should expand Medicare and increase investment in the public provision of primary health care.
    a. Increasing the number of bulk billing general practitioner services and properly supporting general practitioners to provide bulk billed services, should be a high priority policy objective for all political parties and representatives.
2. The Commonwealth government should pursue reforms of the private health insurance industry to ensure that the interests of private health insurers and providers are not being serviced at the expense of Australia's public health system and the quality of Australian public health care.
3. The Commonwealth government should increase the rates for all welfare payments, JobSeeker and the Disability Support Pension (DSP) especially. These increases should be on top of the standard annual rate increases that are pegged to the Consumer Price Index.

Territory

1. The Territory government should examine options for the development, implementation and, where appropriate, expansion of existing community and peer-led services and programs that provide early intervention, social inclusion and non-clinical supports.
2. The Territory government should expand the ACT mental health workforce to ensure adequate staffing of public services by attracting and retaining staff across all levels of service provision.

Introduction to *ACCESS DENIED: A consumer-led study into barriers to accessing mental health services in the ACT*

This Report is a statement by consumers about the barriers that they have been encountering since the COVID-19 pandemic became endemic (2022-present). Consumer feedback was collected through a series of focus groups that were hosted by the Network as the core activity of the project that ran from September 2023 to June 2024.

As well as presenting the voices of consumers who participated in the focus groups, this Report also contains an analysis of the issues, relationships and processes that participants identified and discussed during the focus groups. The Report organises this feedback and links participant experiences with both ongoing local conversations about public health in the ACT as well as broader government, professional and academic discussions about the provision of mental health care in Australia.

What was the Barriers to Access Research Project?

As the ACT's peak systemic advocacy body for consumers, the Network is an organisation run by consumers for consumers. Through our day-to-day work, the Network drew upon ongoing conversations with consumers to devise a research project that would investigate the type and scope of problems that consumers were encountering when they tried to access services. The project was a consumer led and co-designed investigation into the barriers that consumers encounter when they try to access services in the ACT and surrounding regions. The project was made possible by an ActewAGL Community Grant awarded to the Network in September 2023. The project included the focus groups as well as a public survey of the ACT and wider region that collected responses from consumers between April and May 2024. The findings of this survey will be presented in a future study.

The Network designed the project so that the feedback provided by participants in the first round of focus groups was used to determine the topic and focus of the second round. Likewise, the feedback of the second round of focus groups was used to determine the topic of the third round. Participants were informed that their feedback across the first and second rounds of focus groups would be used as the basis for redesigning the Network's biannual survey. The Network undertook this redesign in early 2024 and deployed the new survey for public engagement in May 2024. A draft of this Report was also made available to participants so that additional feedback and comments could be integrated prior to final publication. Through this approach, consumers shaped the design and content of both the focus groups and the survey from start to finish.

How were the focus groups organised and conducted?

Three rounds of six structured focus groups were held:

- Round 1, October 2023, 39 participants.
- Round 2, November-December 2023, 33 participants.
- Round 3, May-April 2024, 31 participants.

Each focus group lasted for two hours. In total, the Network hosted 18 individual focus groups that were attended by 103 participants for a total of 36 hours of discussions. Each round had a tailored structure that was used across all focus groups. The focus groups used a combination of themed discussions and group exercises to gather feedback and generate data.

The focus groups were advertised to members of the Network and to members of the wider ACT community through a flyer that was circulated by the Network as well as associated community organisations. The recruitment advertisement specified that the focus groups were for mental health consumers who have tried to access services and/or supports in the ACT during the last 12 months (mid-2022 to September 2023).

Each participant was allowed to participate in one focus group per round, and they were reimbursed for costs associated with participating for each focus group that they attended (minimum one, maximum three). Many participants attended two or more rounds so that there were 51 unique participants across the project. All participants were informed of the purpose of the focus groups and the Network obtained explicit consent to record and analyse deidentified transcripts of the second and third rounds. Due to the design of the first round of focus groups, no recordings of the round one focus groups were produced or analysed. Importantly, all participants were aged 18 and over. As such, participant feedback focuses on services provided to adults and the findings in this Report should not be treated as indicative of the service environment for child and youth services in the ACT.

The focus groups of the second and third rounds were recorded via Zoom then manually transcribed, deidentified, and reviewed for accuracy. Using NVIVO, the transcripts were then reviewed, organised and coded according to the structure of the discussions used for each round. These transcripts and coding were then analysed by the research team for themes, relationships, and cases emerging from the feedback. Where relevant, the research team drew on publicly accessible reports, government publications and academic literature to contextualise the insights produced by participants over the course of the focus groups. This Report is the final product of this feedback and analysis.

How is the Report organised?

The Report is structured into three sections followed by a general summary. Each section discusses the approach taken for that round of focus groups, presents participant feedback and then analyses this feedback to discuss the prevailing issues and summarise relevant insights. Throughout the Report, consumers who participated in the focus groups are referred to as a *participant* or collectively as *participants*. When a participant is quoted in the Report, their statements are presented in *blue italics* to distinguish their feedback from the rest of the text. This also distinguishes the terms *consumer* and *consumers* that are used to refer to more generally to people with lived experience of mental illness.

The Network has striven to present participant feedback as verbatim statements. This means that many quotes reflect a more conversational style and flow of thought. To ensure a balance between preserving this aspect of the feedback while avoiding overwhelming block-text quotes and confusing syntax, the Network has edited some participant quotes. Care has been taken to ensure that the integrity of participants' statements is preserved. Contractions are indicated with ellipses '*…*' while semantic and typographical adjustments are indicated with square brackets '[ ]'.

Round 1 focus groups: Identifying barriers to access

The first round of focus groups involved participants discussing their lived experiences of encountering barriers to services. This was followed by a group nomination exercise where each participant shared three different barriers that they considered to be the most significant for them. Through this exercise, each focus group created a pool of barriers that were collected, coded and analysed. These codes were reviewed by the project team to ensure consistency and then analysed. The most significant finding from the first round was the diversity of factors that participants identified as being barriers. Alongside commonly recognised barriers such as service location, cost, and capacity, participants also identified a wide range of barriers that related to:

- what services were provided and available;
- the effectiveness of services they accessed; and
- how services were delivered, experienced and perceived.

Through this, participants assembled a broad sense of service inaccessibility that they described as being comprised of material barriers (service unavailability and unaffordability) and holistic barriers (service ineffectiveness) that included barriers relating to the quality of care, interpersonal interaction, and service navigation (see, fig. 1. below).

Reviewing the barriers described by participants showed that participants were encountering known issues that affect mental health systems and which have also been examined in: local ACT community investigations (Capital Health Network (CHN), 2021; Chandra, 2023; Chandra, 2024); professional peak body reports (Thomas & Harris, 2021; The Royal Australian and New Zealand College of Psychiatrists (RANZCP), 2024; The Royal Australian College of General Practitioners (RACGP), 2024); ACT Government reports (Office for Mental Health and Wellbeing (OMHW), 2021; OMHW, 2023; ACT Government: Health, 2023a); and, academic literature (Penchansky & William, 1981; Brown, et al., 2016; Knaak, et al., 2017; Whittle, et al., 2018; van Gaans & Dent, 2018; Bastos, et al., 2019; Kavanaugh, et al., 2023, pp. 12-13; Looi, et al., 2024).

Analysis of the first round of feedback emphasised an aspect of the process of accessing services in Australia that is important for understanding the barriers that participants reported experiencing. Namely, that the systemic organisation of services in Australia places the onus on people who are experiencing poor mental health to *initiate* and *sustain* the process of accessing supports and services (van Gaans & Dent, 2018; Chandra, 2023, p. 13; Chandra, 2024; RACGP, 2024, pp. 11; Teesson, et al., 2024, p. 6).

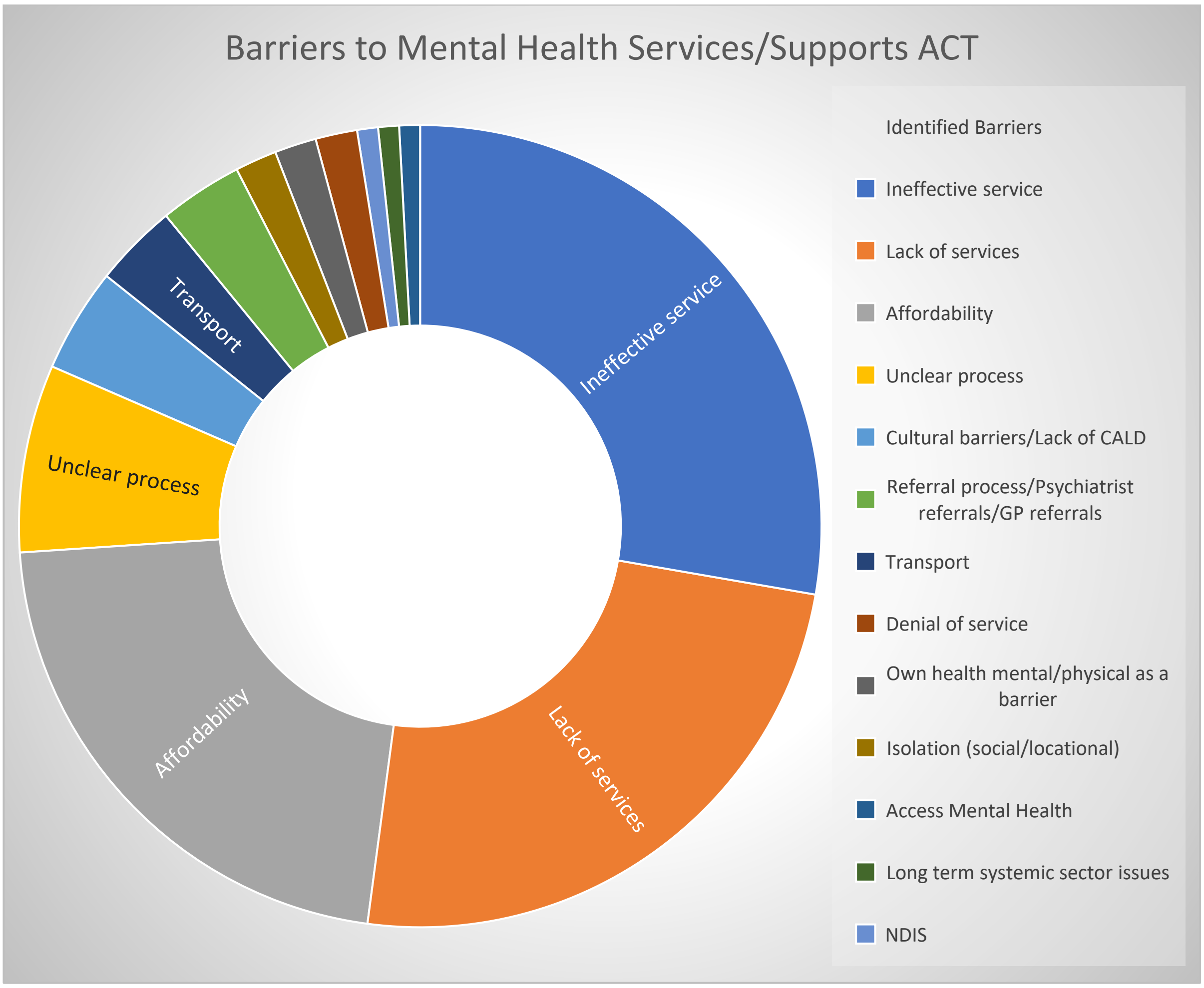

Figure 1 - Round 1, Barriers to access nominated by focus group participants.

The implication of this finding was significant for the remainder of the project and it is a recurring consideration throughout this Report. The reason being that, if a consumer can both afford and physically access a service, but is nevertheless *discouraged* and/or *disincentivised* from initiating and sustaining their engagement with a service due to other factors, then that consumer becomes more likely to either disengage from services they are accessing, or avoid engaging with a service altogether (Knaak, et al., 2017, p. 112; Bastos, et al., 2019, p. 210; Byrow, et al., 2022, pp. 17-18; Chandra, 2023, p. 22; Chandra, 2024).

This insight from the first round stressed the importance of considering both the material accessibility of services (i.e., location, cost and capacity), as well as the holistic accessibility of services (i.e., quality, professionalism, and navigability). As a result, both the second and third rounds of focus groups were designed utilising the barriers identified in the first round. Through this, participants were able to provide further feedback on material and holistic barriers in the system.

In the first round, participants identified ineffective services, affordability of services and the lack of services as the three primary kinds of barriers that they were concerned about. The research team discussed this feedback and here the methodological difficulties of making the topics of affordability and availability of services as two of the three primary focuses for the focus groups were raised. The research team determined that, while discussing affordability and availability barriers using a focus group method would be productive, a survey methodology was better suited to producing insights into and data about these barriers. Due to this, it was decided that the second and third rounds of focus groups would emphasise the investigation of holistic barriers while the redesign of the survey would emphasise investigation of material barriers. This meant that, while both approaches investigated material and holistic barriers, the second round of focus groups were to be focused on consumers' lived experience of encountering barriers. Due to this, the next section explores the consequences to encountering holistic barriers in greater detail than material barriers.

Round 2 focus groups: Consequences of encountering barriers to access

As a result of our findings from the first round of focus groups, the second round was centred on the consequences that participants had experienced due to encountering barriers. During these discussions we used the examples of barriers that participants had identified in the first round as conversational prompts. Importantly, the feedback in this round is not presented as evidence of direct causal relationships between identified barriers and described consequences. Rather, this feedback provides an indication of the range of consequences that participants reported experiencing and the particular barriers that they these experiences to. With this in mind, the focus groups of the second round were structured around discussions of each type of barrier that were presented as follows:

1. Quality of care barriers;
2. Interpersonal interaction barriers;
3. Service navigation barriers;
4. Affordability barriers; and
5. Availability barriers.

The consequences reported by participants across the different types of barriers were many and varied. However, it was the longer-term consequences for participants after encountering one or more of these barriers that stood out. For example, some participants reported that encountering these types of barriers had affected their trust of a service provider and subsequently led them to disengage from ongoing care. Likewise, negative prior experiences with a service provider led some participants to delay or forgo seeking assistance even when their mental health situation worsened at a later point in time. In more serious instances, participants reported that encountering multiple barriers had jeopardised their safety in the short term and severely affected their wellbeing in the long term.

1. Quality of care barriers

Quality of care barriers are encountered by consumers once they have initiated their engagement with a service or program. Due to the structure and organisation of the system, accessing a service often involves engaging multiple services for successive appointments and with a variety of services and professionals (Chandra, 2004, p. 20; RACGP, 2024, p. 11). For instance, a person may need to see a general practitioner (GP) to receive a referral for a psychologist with whom they may have several appointments before being referred to another service or specialist (Thornley &

Harris, 2021, pp. 25, 36; RACGP, 2024, pp. vii, 3-5). If a person experiences poor quality care at any stage of this process, then their capacity to initiate and sustain their engagement with services may be undermined (Knaak, et al., 2017, p. 112; Chandra, 2023, pp. 26-27). The result is that a person who has already accessed some services, may disengage from those services and/or be reluctant to reengage with them in future (Brown, et al., 2016, p. 4; Knaak, et al., 2017, p. 112). It is in this way that a service's quality of care can become a barrier to access.

Specifically, participants described a relationship between:

- Their experiences and perceptions of poor quality of care from service providers;
- The negative consequences they experienced as a result of poor quality care; and
- The effects of these experiences for their capacity to engage, continue engaging, or reengage with, mental health care service providers.

And participants articulated this relationship through four kinds of consequences that they reported encountering:

- Feeling inadequate as a person;
- The exacerbation of their mental health illness;
- Negative impacts on their employment; and
- An increase in negative sentiment towards services.

One participant described the consequences they experienced from the misdiagnosis of their mental illness:

> *This was all shaped around a misdiagnosis that stuck with me for over a decade until someone finally identified PTSD* [Post-Traumatic Stress Disorder] … [the misdiagnosis] *led to like, you know, poor self-esteem, unable to get employment, losing employment, and significant consequences for my partner.*

Another participant linked the exacerbation of their mental illness to poor quality services:

> [W]*hen the service is not good and you're not getting want you want, then you lose hope, you lose, lose faith and trust, and you may get worse. Your condition may get worse.*

Participants repeatedly stressed that the consequences of encountering barriers are rarely contained and frequently have 'knock-on-effects' that affect other aspects of their lives. One participant described one such knock-on-effect in the context of their workplace where difficulties with managing appointments and stigma led to consequences for how they were treated at work:

> *I haven't had reduced hours, but I've had like, I'm having performance management, I guess, at work. And, you know, a lot of like, making me feel bad, you know, like the shame that comes with that and stuff. And yeah, financial, the constant ongoing expense is certainly a consequence, like having to repeatedly get appointments to deal with things*.

Another participant described the same issue but in terms of their social life:

> *If I don't get a good, competent counsellor, I don't feel like going again … that led to isolating myself socially because I know I have a problem but I know it's not been dealt with so I don't feel like going and meeting other people*.

Low quality care that resulted in feelings of invalidation, inadequacy or stigmatisation were also linked by some participants to self-medicating behaviours that present their own potential health complications. In the experience of one participant:

> *I didn't feel like I was listened to at all. … I felt worse about myself. It just reinforced that I didn't matter. I wasn't listened to. I actually went home, and I started to drink every night to try and numb the symptoms. I have never drunk in my life before then.*

Likewise, another consumer recounted an experience that, after they were prescribed "*antidepressants to treat what wasn't a depressive issue … led to high dependence on illicit drugs to self-medicate and just be able to cope*".

Participants also drew connections between experiences of low quality care, complications arising from prescription medications, and negative outcomes. For example, one participant said that they had:

> [B]*een put on the wrong medication several times, and because of my natural condition they exacerbated it … pretty negative effects such as violence, complete psychotic breakdown.*

Other participants had similar experiences with one who stated that they had been: "*on various medications that affected me physically as well as affected me financially*". Meanwhile another participant reported that they:

> [W]*ent through six or seven different medications. None of them really worked back then. Or they made me like, like feel like I was a robot, you know? Just taking all my emotions away.*

Such experiences underscored the consequences of poor quality care and participants drew strong links between these experiences and their capacity to initiate and sustain engagement with services, with disengagement from services being a notable consequence. One participant stated this bluntly: “*Medical distrust has made me less likely to find help that I needed.*” Another reported:

> [T]*he biggest impact of this is, I think, a real like service fatigue … it’s really hard to reengage, and obviously that is sort of a spiral, sort of a snowball effect*[.]

Indeed, one participant explained that such experiences had affected their beliefs and perceptions about the system as a whole:

> *I feel less trusting in utilising health care services essentially, and more inclined to think that my likelihood of improved quality of life through further treatment is shakier.*

Participants had strong perspectives on the consequences of poor quality of care. Disengagement from services and a reduced capacity to initiate and sustain engagement with the system are noteworthy consequences that can become barriers by disincentivising re-engagement and/or future engagement (Knaak et al., 2017, p. 112; Byrow et al, 2022, pp. 14-15; Chandra, 2023, p. 26; Looi et al., 2024). Nonetheless, this barrier is ultimately one that service providers exercise an important degree of control over (Knaak et al., 2017, pp. 112-113). Namely, participants are more likely to have positive care experiences when services providers collaborate with consumers to undertake effective mental health care that matches accurate diagnoses with appropriate interventions.

2. Interpersonal interaction barriers

Interpersonal interaction barriers primarily arise due to how services are delivered and how this affects a consumer’s capacity to initiate and sustain engagement with services (Chandra, 2023, p. 21). Interpersonal interaction and quality of care barriers share many similarities and overlaps in that both occur in the context of how services are provided. For instance, discrimination can be considered as a quality of care barrier as well as an interpersonal interaction barrier (Bastos et al., 2019; Knaak et al. 2017, p. 112). Likewise, both types of barriers require a person to engage with a service, at least to some degree, before they can encounter them. For instance, by making a phone call or visiting a service. Furthermore, both types of barriers can have longer term consequences, such as creating distrust between a person and a service provider or causing a person to feel demotivated and lead to them disengaging from a service (Knaak et al., 2017, p. 112; Birkhäuer et al., 2017, pp. 8-10; Byrow et al., 2022, pp. 16-17).

Interpersonal interaction barriers involve issues such as stigma, inadequate linguistic and cultural accessibility, and discrimination (Rose et al., 2018; Byrow et al., 2020; pp. 16-18; Chandra, 2023). Interpersonal interaction barriers can therefore occur in all aspects of a service's operations, whether in their reception, patient management, staff attitudes and/or external patient communication (Knaak et al., 2017; Rose et al., 2018; Chandra, 2023).

In the domain of interpersonal interaction barriers then, participants reported several issues and consequences. Lack of professionalism was cited as the biggest issue with stigmatising and culturally insensitive interactions also being highlighted. What stood out, however, were the types of consequences that included:

- loss of trust in the support or service;
- fear of engaging services; and
- severe emotional distress.

Loss of trust was a major consequence reported by participants when encountering interpersonal barriers. For example, a participant related how their sense of trust was impacted after experiencing an interaction where a service staff member lacked professionalism and exhibited stigmatising behaviour: "*I couldn't trust her again. … I just felt, 'oh my God!' … 'she is my nurse?' How am I going to meet her or trust her or even report to her?*"

Likewise, as another participant stated in the context of experiencing culturally insensitive interactions, there is:

> [J]*ust a lack of understanding when you come from different cultural backgrounds. It can be quite tricky. But in terms of the consequences of those is just a lack of trust in the service providers I think.*

The potential consequences of encountering interpersonal interaction barriers when engaging with crisis services were highlighted by one participant who stated that such negative interactions had "*completely invalidated me*" and that they had felt "*devastated*". They summarised their experiences as follows:

> [I]*t's just a very traumatic process because they don't often take you seriously. They'll often send you home and, you know, I've used my last money to get there … and they will just say 'there's nothing we can do for you', and when you're in a crisis, that's just totally invalidating.*

Some participants drew direct connections between their negative interpersonal interactions and subsequent attitudes toward initiating or sustaining their engagement with a service. One participant described how:

> [Y]*ou can be made to feel abandoned or rejected quite often by the people within the system. And so, I've learned to avoid this system myself because I'm trying to avoid those feelings, of rejection and abandonment.*

Similarly, another participant related how in their experience:

> [T]*he response is just for people to kind of talk down to me and get angry. It's definitely a barrier. It's made me not want to go to the doctor. It's made me not want to go to psychiatrists.*

The consequences of negative interpersonal interactions weren't limited to emotional distrust, service disengagement or service aversion, but extended to additional financial impacts and treatment delays. One participant stated how negative interpersonal experiences with a service that they had been referred to led them to disengage and search for another provider:

> *It was terrible, and I had to go back to the original GP that we'd seen … we had success eventually. But a consequence was a considerable holdup in the whole process, a lot of running around*.

Another participant highlighted how:

> *Following up on bad experiences just takes a lot of energy. Finding complaints processes, following up on discrimination processes. …* [it] *takes a serious emotional and financial toll*.

The importance of positive interpersonal interactions in service settings was further demonstrated by one participant who described the impact that positive interactions had had on their capacity to initiate and sustain engagement with services: "[T]*he more confidence you have, the more you can believe that you can get out there and work out what you want, where you can go, and what you need.*" Though not expressed in the context of the interpersonal interaction barriers discussions, this sentiment was strongly echoed by a different participant when they described their experiences with their GP:

> *I'm super lucky with my doctor … I can tell her … This is happening, and this is happening, and she'll be like, 'Okay, so we need to do this to send this. I'm going to give you a referral to here.' …* [S]*he is not judgemental. She's a hundred percent supportive. … my doctor is the one place where I feel safe. I would not call Access Mental Health in a crisis, but I would definitely call my doctor.*

These two examples indicate a relationship between positive interpersonal interactions, trust and a person's capacity to initiate and sustain engagement with services. To the extent that service delivery has the potential to increase a consumer’s capacity to initiate and sustain engagement with services, it should therefore be treated as a serious dimension of service provision.

As with quality of care barriers, participants reported that interpersonal interaction barriers had the potential to discourage and disincentivise them from initiating and sustaining their engagement with services. The types of reported consequences highlighted the importance that participants placed on being able to trust, feel heard by, and have compassionate interactions with the service staff that they interact with.

This feedback emphasises the role of service delivery as an important dimension of service provision, rather than a secondary consideration. It also underscores the role that *all* service staff play in providing services (Knaak, et al., 2017, p. 113; Birkhäuer, et al., 2017, p. 9; Chandra, 2023, pp. 13, 21-22), whether they are a receptionist, dispatcher, or professional. This stresses then the diligence that service providers need to maintain when educating and training front line staff who may, or are expected to, interact with consumers experiencing poor mental health. Additionally, it suggests that issues such as compassion fatigue, burnout and the inadequate support of service staffs’ own mental health needs, are important risk factors that service providers, with the proper support of Commonwealth and Territory governments, need to mitigate in their workplaces (Knaak, et al., 2017, pp. 112-113; CHN, 2021, p. 111; Chandra, 2023, pp. 22-23; RANZCP, 2024; Looi, et al., 2024).

3. Service navigation barriers

Service navigation barriers occupy a distinct but important space in the framework of holistic barriers to services: How easy or hard is it to find an appropriate service, book an appointment, and access the guidance and/or care needed? Notably, while the first round of focus groups identified service navigation barriers as a subset of holistic barriers, it was during the second round that participant feedback clarified what, in their experience, this barrier entailed. Because of this, this section contains a more extended discussion of the nature of the barriers described by consumers. The issues that participants reported as being service navigation barriers can be summarised as follows:

- Not knowing what services are locally available, and what kinds of care they have the capacity to provide;
- GPs and clinics lacking adequate and current information about options in the system beyond crisis and emergency services;
- Maladministration within and between service providers that creates delays in, or obstructions to, accessing and progressing care; and,

- Managing multiple bureaucratic processes in order to initiate and sustain engagement with services.

An element of this feedback that stood out was the diversity and complexity of factors involved in participants' experiences of encountering service navigation barriers and the consequences that participants attributed to these barriers. Due to this, the nature of service navigation barriers needs to be discussed before the consequences reported by participants can be presented.

The factors that give rise to service navigation barriers occur across three distinct but overlapping fields of service provision (Thornley & Harris, 2021, pp. 22-26, 32-33; CHN, 2021, pp. 60-61; Chandra, 2023, pp. 22-24; Looi, et al., 2024):

- Within a service provider (the intra-organisational field);
- Between service providers (the inter-organisational field); and
- Across the national and local system within which services operate (the systemic field).

The factors that create barriers to navigating services can be:

- Incidental (intra-/inter-organisational fields), that is, unintended accidents and errors in service delivery and/or implementation.
- Infrastructural (intra-/inter-organisational and system fields), that is, the features of a service or the system – or the absence thereof – such as service promotion or linguistic supports (CHN, 2021, p. 60; Chandra, 2023, p. 24).
- Structural (inter-organisational and system fields), that is, the features of the system that govern service operations such as legislation, regulation, and funding arrangements (Thornley & Harris, 2021, p. 23; Chandra, 2023, p. 23; Looi et al., 2024).

Additionally, these factors can interact with and compound each other such that the causes of service navigation barriers are plural and difficult to address (RACGP, 2024, p. 14; Looi et al., 2024). Problems such as insufficient funding arrangements or clear public policy direction (the systemic field) can lead to improper practices or ad hoc solutions by service providers (the inter-/intra-organisational fields) that create practical dilemmas and obstacles for the service staff who provide care and support to consumers (the intra-organisational field). For the consumer, they may experience this barrier as the simple, but profoundly frustrating, fact that their 'information was lost' or their 'appointment wasn't successfully booked'; yet the actual causes of this experience may be much more complex than a mere mistake by service staff.

Appreciating this, it is therefore important to keep in mind the plural causes of holistic barriers that complicates both the analysis of participant feedback as well as the process of addressing such barriers through policy responses. With this established, we can now review the feedback received during this section of the focus groups to see how participants described their experiences of service navigation barriers.

The feedback received by the Network illustrates both the above conceptualisation of service navigation barriers as well as how participants experienced them. For example, one participant described how issues with record management and communication within and between two services prevented them from accessing care:

> *So, you get your referral … you hand it off to the receptionist however and they go 'We'll send it on',* [but] *then the other side doesn't receive it, or they don't process it properly. And then you get left in the gap between. We are not told what's going on, and there's no procedure to follow it up.*

This issue was also raised by another participant who stated that "*services to services, they don't communicate … and it just gets lost, like, case notes and stuff gets lost.*" Likewise, some participants reported issues with service connection and follow-up with one participant recounting that the service provider they were engaged with were:

> [G]*oing to contact the public mental health team I'm linked with directly, and they were going to do a referral to a service that would give me twelve weeks of support. And it turns out that they did neither. … I got left hanging for seven to eight weeks.*

In these examples, the barrier encountered by the participant arises at the intra- and inter- organisational fields. That is, an administrative and/or communications issue within and between the two service providers prevented the participant from progressing from one service to the next, resulting in delayed care and distress.

In a different example of a type of service navigation barrier, a participant described how knowledge and information gaps hindered their ability to access care:

> *I've gone to the doctor and explained what's wrong with me and I just find that they don't have all the skills. They don't know the opportunities that are out there. … So, you go home, and sometimes you have to look through it yourself, or someone else might suggest things to you. … The doctors sometimes don't have all up to date information.*

In this case the barrier is operating in both the system and intra-organisational fields: neither the GP nor the participant were able to access up to date information about available services. Other participants reiterated this point with one explaining that they often found: "*GPs just not knowing where to refer to, like, relying on the patient* *to say, like, 'I want to go with this person, or that person'*", while another stated that, in their experience:

> [T]*here is just a lack of knowledge of what services are provided within the community, and which ones are free and easily accessible, and what kind*[s] *of document and paperwork is needed*.

Feedback such as this indicates that there is a broader system-level issue where comprehensive information about local services and supports is not readily accessible to GPs and consumers (Thornley & Harris, 2021, pp. 25-26; CHN, 2021, p. 47). Exacerbating this issue, Commonwealth and Territory policies direct people experiencing poor mental health to initiate their engagement with services by consulting with their GP (Thornley & Harris, 2021). Consequently, if general practitioners are not adequately equipped with up-to-date information resources, then a serious service navigation barrier arises (Thornley & Harris, 2021; CHN, 2021, pp. 33, 37-38; Chandra, 2023, p. 18; RACGP, 2024).

This feedback also highlights the importance of GPs having access to information about community services and groups that are free or low cost and that may offer peer and lived-experience programs. An advantage of such community services is that their programs can offer forms of social inclusion for consumers that are absent from clinical and transactional models of care. A private psychologist or psychiatrist can provide clinical insight, support and administrative access to other supports (medication, public programs, etc.), but they do not necessarily provide friendship or a sense of social belonging. While it is beyond the scope of this report to argue the case for the role of friendship and social belonging in the process of stabilisation and recovery, it is by no means controversial to propose that they are vital to holistic wellbeing. As participant feedback later in this Report will attest, it is perhaps time for policy makers to give greater consideration to how clinical care options can be complemented by community programs that both support consumers and promote social inclusion.

These, then, are some of the ways in which factors operating across different fields of service provision can create service navigation barriers for consumers. As indicated, service navigation barriers can be complex in nature and may not be reducible to service provider level factors (Thornley & Harris, 2021, pp. 11, 22, 34; CHN, 2021, pp. 47, 60-61; Chandra, 2023, pp. 18-21). Indeed, participant feedback suggests that it is how factors operating across the different fields of service provision combine with one another that determines how consequential service navigation barriers can be. With this in mind, we can consider the consequences that participants reported.

As with quality of care and interpersonal interaction barriers, participants described personal stress, treatment delays, and service disengagement as major consequences. However, unlike quality of care and interpersonal interaction barriers, participants tended to report *sequences* of problems that *cumulatively* led to the consequences they reported. Participants rarely attributed the consequences they experienced from service navigation barriers to a singular incident, but rather to multiple, or repeat, instances of similar problems. For example, as one participant recounted:

> [J]*ust because of something happening – the practitioner being sick, or the admin missing something that just falls in the cracks – you don't know you've fallen into the cracks. … When's the phone call? When's my next appointment? And it's like, because you don't know that you've been moved out of the system,* [and] *for whatever accidental or intentional reason, you can't then follow up. And, when you do follow up you have to go back to the very start which takes all your time and all your money to do everything all again.*

Here, the participant identified a series of issues arising from incidental maladministration, the experience of which they summarise as of having "*fallen through the cracks*", and the consequences of which are the loss of their time, effort, and money. Another participant expressed similar sentiments:

> [Y]*ou just get lost in the system … it's a pile of referrals essentially, it's a pile of intake information. … it's kind of up to the consumer to keep, essentially, bothering the service, to try to get the appointment that's needed, or what you're waiting for.*

This example underscores the administrative burden placed on consumers to manage documentation and chase up services as they navigate the system. The consequences here are both the risk of failing to navigate the system – of getting 'lost' – and the cost to the consumer in terms of their wasted time and effort. These sentiments were repeated by another participant who reflected that:

> *It takes a lot of perseverance. And I think a lot of, you know, people just give up basically in trying to navigate the services unless you have peer support or somebody that's willing to help you go through it. Somebody that's, you know, used to dealing with bureaucracy and filling out forms and all those other things.*

This highlights an often under considered aspect of navigating services, namely, that people are undertaking this process while experiencing poor mental health and may require additional support to overcome knowledge gaps, manage administrative tasks, and ensure that any lapses in process are promptly corrected (Chandra, 2023, p. 19; RACGP, 2024, p. 11).

Service navigation barriers can be appreciated as the *friction* within a system that consumers must overcome as they locate, access, and move between services. Thought of in this way, service navigation barriers affect a consumer's capacity to initiate and sustain their engagement with services by imposing cumulative time, money, and personal energy costs (Whittle, et al., 2018, p. 87; Chandra, 2023, pp. 18-22; Chandra, 2024, pp. 19-24). Concurrent with this is that consumers with comorbidities and/or who need access to multiple services, will be more likely to encounter service navigation barriers and thus need to overcome more friction (Whittle, et al., 2018; CHN, 2021, pp. 60-66; Chandra, 2023; Chandra, 2024).

Considered in these terms, the consequences of service navigation barriers described by participants were not necessarily as severe or far ranging as those reported for quality of care and interpersonal interaction barriers. However, the nature of service navigation barriers as *recurring* issues produced by features of services and the system means that they can have outsized effects for consumers who have limited resources to expend on managing and monitoring the various processes involved in navigating services. Due to this, the impact of service navigation barriers cannot be underestimated, especially for consumers who need to access multiple services, manage chronic conditions and have limited personal resources (Chandra, 2023; Chandra, 2024, p. 29).

This feedback sheds light on a category of barriers to services that can be difficult to specify and quantify due to how they are experienced by consumers. Namely, navigation barriers are experienced as a series of absences (e.g., a lack of information or guidance), accidents (e.g., maladministration, poor communication), and missed opportunities (e.g., scheduling conflicts, staffing issues). With service navigation barriers taxing a consumer's time, money, and energy, the friction that such barriers create within a system can exhaust people and lead to disengagement from services (Chandra, 2024, pp. 19-24). Moreover, when situated alongside quality of care and interpersonal interaction barriers, service navigation barriers create an additional layer of frustration that adds to the stressors that can arise when initiating and sustaining engagement with services.

The complexity of the factors that contribute to consumers' experiences of service navigation barriers also re-emphasises the importance of taking a holistic perspective to understanding and addressing barriers to services. On the one hand, reducing service navigation barriers requires both service providers and the Territory government to collaborate in improving service pathways and information resources (Thomas & Harris, 2021, pp. 25-26; CHN, 2021, p. 47; Chandra, 2023, pp. 22-27).

On the other hand, some degree of friction in the process of accessing services is inevitable in that accessing care takes at least some time, effort and money on the part of the consumer. However, it is important that the Territory government and service providers take all reasonable steps to reduce avoidable friction points across the system to reduce the burdens being experienced by consumers. In this regard, one of the points of intervention highlighted by this feedback is the need for comprehensive and up to date information resources that detail the available supports and services in the system which is accessible by service providers and the general public.

4. Affordability barriers

As noted in the introduction to the Report, discussions regarding material barriers received less attention during the focus groups. Nevertheless, discussions concerning the consequences of encountering these barriers were still insightful. Participants identified three major consequences arising from encountering affordability barriers:

- reduced physical and mental wellbeing;
- financial stress; and
- increased social isolation.

A feature of these discussions were the participants' observations of the compounding nature of consequences arising from services being unaffordable. One participant eloquently summarised this aspect in terms of 'cascading consequences':

> [W]*e're describing a cascade of consequences. If people can't access the right appointment and support at all, and this is now the reason being about cost, but essentially, if your mental health is not addressed appropriately and you're not supported appropriately, there's the potential for a whole cascade of mental, physical and environmental impacts.*

The knock-on effects of unaffordable services extended to family, work, friends, and the deteriorations that participants reported in these areas of their life in turn worsened their mental health. As one participant reported:

> *I've got physical health injuries and I've been going for two years through the public system to try and get the issue fixed which is putting me in more pain, less mobility. And that worsens your mental health, big time, and you feel like you're not worthwhile*.

Participants drew connections between being unable to afford to access services and a reduced physical and mental wellbeing. As one participant summarised:

"[T]*here's such a strong interaction or intersection between our mental health issues and our financial situation*". Some participants reported having to make trade-offs between necessities: "*How am I going to pay my rent? Or am I going to choose to pay my food? …* [or] *am I going to choose to go to my psychologist?*". Another expressed that: "*It's just living with the realities that you can't afford anything, but you do have to afford, well for me, I have to afford my psychiatry, I couldn't be without that.*" Likewise, one participant noted the impact on their weekly grocery shopping: "*I can't remember the last time I bought proper vegetables and fruit and stuff like that*".

For each of these participants, struggling with such financial burdens was a no-win situation. On the one hand, choosing necessities often meant forgoing the supports they were seeking to improve their wellbeing. On the other, forgoing necessities may have enabled accessing supports, but their wellbeing suffered in other ways. In either circumstance, participants reported that difficulties with affording services created their additional problems and stresses. For example, one participant recounted that for them: "[I]*t is literally living till the pay cheque to prioritise treatment and support*". Another highlighted the emotional impacts of the financial burden:

> [Y]*ou feel a huge amount of shame, like you rely on the kindness of others … because how else are you supposed to get yourself out? How are you supposed to address your mental health?*

The impacts of such financial stress are not limited to the consumer, it is associated with strained family relationships (ACOSS, 2024, p. 9). As one participant recounted, for them:

> [E]*veryone is on a knife's edge in your family because everyone's not doing well, and nobody's getting support. Like, it just escalates the conflict and sort of makes home less safe.*

Likewise, another participant highlighted the burden that unaffordable services created for their partner:

> *I am highly dependent on my* [partner]*, basically to fund my mental health care. … But I feel like, you know, it's not fair that I'm reliant on* [them] *to have to cover everything*.

Social isolation was the third major consequence reported by participants and, given its documented links with depression, emotional distress and suicide (Smith & Victor, 2019; Usher, et al., 2020; Postolovksi, et al., 2021), it is a consequence of noteworthy concern. As one participant described:

> *I'm at the age where all my friends are retiring, and that they're all, you know, travelling all the time and stuff like that. So, I'm never invited, because I know I can never afford it.*

Similarly, another participant noted how: "*You can't really participate in a lot of social things. You can't have hobbies and that sort of thing because everything's just for living.*" This highlights a common challenge faced by consumers with significant ongoing mental health expenses (Wang, et al., 2022). Namely, that many avenues of social inclusion are gated behind a variety of expenses such as transportation, equipment and/or participation fees (ACOSS, 2024, pp. 17). As another participant stated: "*You cannot afford to go out with friends so you can't maintain social networks.*" Likewise, a separate participant related how the loss of social connection can cause significant emotional distress and exacerbated the symptoms of their mental illness: "*You go into a period of despair because you can't, you can't afford your medication. You lose friends and family, people think you're weird.*"

The compounding and cascading effects of affordability barriers described by participants also overlap with other social stressors that consumers may be experiencing independently, or as a result, of poor mental health (Chandra, 2023; 2024; ACOSS, 2024). For example, consumers who are unsupported or under-supported due to affordability barriers may experience a reduced earning capacity that increases their financial stress and risk of housing instability while also lowering the resources they have to meet basic material needs and afford services (Wang, et al., 2022, p. 2; RACGP, 2024, p. 8; ACOSS, 2024, p. 9). However, maintaining employment does necessarily mean that affordability barriers cannot still have serious consequences. As one participant stated:

> *I think one consequence also of unaffordable services and support, is feeling the need to work more to be able to afford that, which can then lead to burnout and also your mental health deteriorating as well.*

This feedback from participants underscores the severity of the burdens that can arise from affordability barriers and the vicious cycle of stress, dwindling resources and worsening physical and mental health that many participants reported experiencing (ACOSS, 2024, pp. 13-14; RACGP, 2024, pp. 11, 35). In view of this, it is critical for people experiencing poor mental health to be able to access timely support that does not depend on whether or not they have a sufficient reserve of financial resources to sustain their engagement (RACGP, 2024, pp. 11, 17; Looi, et al., 2024).

5. Availability barriers

Feedback from participants across the first round identified two distinct subcategories through which availability barriers may be understood:

- A service is unavailable due to the absence of service providers in the ACT.

- A service is present in the ACT, but it is functionally unavailable due to insufficient capacity and/or location.

The focus of this discussion was on the consequences that participants reported experiencing rather than on the identification of which services were or were not actually available in the ACT. Furthermore, when participants reported that a service they needed to access was unavailable due to the absence of providers in the ACT, the possibility exists that they may simply have been unable to locate information regarding available providers. In such cases, the participant's reported experience of a perceived availability barrier may instead indicate that they have encountered one or more service navigation barriers. Due to this, participant feedback in this section should be treated carefully because it is not possible to retrospectively determine whether a participant tried to access an unavailable service or encountered a service navigation barrier. Bearing this in mind, most feedback from participants concerned barriers and consequences relating to services that are present in the ACT, but which participants deemed to be unavailable due to either a lack of capacity (closed books, long waitlists, etc.) or the location of the service being too distant for them to reasonably attend.

With regards to services that participants reported being unavailable due to a lack of ACT service providers, specific specialist and culturally competent services were the primary types that participants experienced availability barriers with. For example, the unavailability of both gender affirming services and health services with practitioners trained to provide care for gender and sexually diverse people presented a distinct set of consequences. Gender affirming care attends to both physical and mental health needs and as such a lack of specialist gender affirming medical service providers creates onerous availability barriers for consumers who have need of these services (CHN, 2021, pp. 64-65; OMHW, 2021). The consequences of availability barriers in these contexts can be extremely disruptive. As one participant explained:

> *I had to travel to Victoria, which was a massive commitment in terms of finances and employment. Like, I had to take 6 months off work for recovery and spend up to ten days in Victoria because of the needs for follow up appointments.*

Similarly, a lack of both physical and mental health practitioners with appropriate training in providing care for gender and sexually diverse people means that such participants risk receiving inadequate and insensitive care (CHN, 2021, pp. 64-65; OMHW, 2021). This can lead some to forgo accessing services altogether to the detriment of their own wellbeing. As one participant recounted with respect to a friend: “[T]*hey didn’t feel like they had the confidentiality of like, going to services that would understand*”.

For participants requiring culturally competent services and/or services with multilingual practitioners, the absence of such services in the ACT can have consequences similar to those reported by gender and sexually diverse participants. Namely, there are risks that consumers will receive inadequate, inappropriate and/or insensitive care that can discourage and disincentivise them from initiating engagement with services (Byrow, et al., 2020, p. 16). As one participant described:

> [W]*e don’t want to go see that GP, because we’ve got our cultural issues and language issues. We want to go see these people where there’s a Nepalese GP. However, if there’s not a big enough cultural group, enough demand, there’s going to be no* [such] *service.*

Likewise, negative experiences with and perceptions of services that lack linguistic supports and cultural competency can reduce trust among culturally and linguistically diverse communities and decrease the likelihood the members of these communities will engage with the system (Brown, et al., 2016; Bastos, et al., 2019; Byrow, et al., 2020, pp. 17-18; CHN, 2021, pp. 65, 82; Kavanagh, 2023, p. 13).

For some participants for whom services were unavailable in the ACT, they opted to pursue services interstate, predominantly in NSW near the borders of the ACT, and sometimes as far as Sydney. For these participants, the consequences of having to rely on interstate service providers were substantial and resulted in both serious financial burdens and disruptions to their employment. One participant reported:

> *I have to travel interstate so New South Wales, Sydney and that’s what I’ve done for twelve years. I have to rely on others when I drive, because there’s no way I can get to New South Wales without driving. … I had to pay for us to stay at a youth hostel overnight, and plus all our meals and all that. So, it’s not just the cost of going to the psychiatrist.*

Similarly, another participant recounted that:

> *I had to turn down shifts, because I knew I’d had like two hours of travel there and back, plus the forty-five-minute appointment. And like, financially, during the time I was travelling, petrol was really expensive, and I was doing these trips like every couple of weeks.*

For participants who needed services that weren’t provided in the ACT but couldn’t afford to travel interstate for support, then the only choice may be to forgo support altogether: “[I]*f they’re not available in the ACT, obviously then you can’t access them*”. Here, then, overlaps between availability and affordability barriers can be observed in action. An absence of local services creates additional affordability barriers as consumers need to travel further and cover additional costs to access services.

Throughout the discussion, participants described how availability barriers undermined their ability to maintain their mental health, recover from periods of increased distress, and worsened their overall wellbeing. Notably, consequences such as these were not just reported in cases where specific service providers were absent from the ACT, but also when ACT services were unavailable to participants due to waitlists and/or location. In this respect, personal stress, financial burdens, and the impacts on employment were the major consequences that participants reported as a result of encountering availability barriers. A common cause that participants identified for such consequences were waitlists. As one participant described:

> [T]*here's a seven-month waiting list. So, I didn't actually complete the process to go with them. I didn't go in to fill out the paperwork, because when I found out there was a seven-month waiting list*.

Likewise, another participant recounted how scheduling conflicts and waitlists caused stressful delays in their treatment:

> *So, they just assume that because you're a mental health consumer that you have nothing better to do with your time, but to be available for their appointments. Because I get appointments made for me, and sometimes I'm not free … but if you can't show up to their original appointment, you can take another month or two to get in to a psychiatrist.*

In both cases, waitlists and scheduling complications operated to disincentivise and discourage the consumers from sustaining their engagement with services. In the case of the former, they disengaged from the process while for the latter, they experienced frustration and incurred stress.

Other participants noted that a lack of capacity in services meant that they turned to providers without expertise in mental health care. For example, as one participant recalled:

> *There are definitely GPs out there, but many have closed books, and most have closed books and as a result you have treatment and care provided by someone for whom mental health is not their speciality area. And so that's suboptimal and that can lead to a sense of feeling misunderstood and invalidated as a patient.*

Insufficient capacity with specialist providers was also reported as a factor that created significant problems:

> *There's only one like, psychologist in the ACT who has specialty in OCD* [obsessive-compulsive disorder]*, and does the most evidenced based therapy for OCD … and basically everyone else does CBT* [cognitive behavioural therapy] *… I've been on that person's waitlist since 2020, it's not an ideal situation.*

Similarly, another participant explained how waitlists had impacted their employment:

> [N]*ot being able to access services, adequate services in a timely manner …* [led] *to me needing to use up all my sick leave, and it took months and months to recover.*

Participants identified the location of services in the ACT as an aspect of availability barriers that created problems for them, particularly with regards to transportation. Participants reported that relying upon interstate services for essential care often meant incurring additional financial burdens and personal stress that impeded their ability to maintain their employment. Participants also connected such experiences with a reduction in their capacity to initiate and sustain their engagement with services in the long-term. For example, one participant described their experience with public transportation:

> *I'm catches buses, and because of where I had to go to it was sort of quite a walk up-hill, away from the main route. You had to get off your rapid bus and sort of walk the long distance. …. But the worst thing was after …* [because] *you could be sitting up the top of, you know, CIT* [Canberra Institute of Technology] *for having to wait half an hour within winter as well. … And I just gave up on the program.*

Another participant highlighted how, for them:

> [H]*aving to walk up the hill …* [it] *used to be a direct rapid bus route. It's really difficult to actually attend services, and I think location is really, you know, should really be a big consideration … if you don't drive, you're dependent on buses*.

Travel to services outside of the core bus routes and encountering scheduling delays also made attending services more time consuming and physically exhausting. Furthermore, just as with affordability barriers, participants identified the consequences of availability barriers as having knock on effects for other aspects of their life:

> [W]*e can't get services and support, so* [your] *mental health declines and that then has a massive impact on being able to, I guess, function, maintain relationships with family and friends, do anything social. The worse you get, the harder it is to actually do anything.*

Once again, feedback about this barrier to services underscored the additional barriers and complications faced by consumers who do not have sufficient financial resources to accommodate the range of ongoing expenses and loss of income (Wang, et al., 2022; RACGP, 2024, p. 35; Chandra, 2024, pp. 19-20). Indeed, it reinforces a consistent theme of the focus groups. Namely, that consumers with the highest needs also tend to have the fewest resources and thereby face the most barriers to services.

Summary of the second round of focus groups

Two key themes emerged from the second round of focus groups:

- Holistic and material barriers to services are multilayered, intersecting and compounding.
- The consequences of encountering barriers are manifold, compounding, and can have long term effects on a consumer's capacity to initiate and sustain their engagement with services.

Importantly, the barriers and consequences described by participants arose in the contexts of engaging with multiple types of service within the system. For some consumers, their engagement with the system may be relatively linear. For instance, a consumer may consult with a GP regarding a mental health concern, be referred to a service that recommends a short-term treatment and, after this process, the consumer's health stabilises and their engagement with services concludes. However, many participants described experiences of the system that were non-linear, cyclical and/or continuous. For such participants, barriers to services were persistent and recurrent features of their experience that drained their resources, sapped their energy, and, in cases, worsened their overall health rather than improved it. As one participant related:

> *It's sort of a triggering, a downward spiral or exacerbation of problems, of one thing begetting the next, which begets the next, and I don't know how to get out of it, and if you fall into the gap … it becomes a problem of relapse.*

It was this aspect of the second round of focus groups that indicated the direction for the third round, namely, to discuss participants' holistic experience of accessing services in the system and detail the changes they would like to see made.

Round 3 focus groups: Holistic experiences & recommendations for change

Participant feedback from the second round highlighted how the layering of, and recurring encounters with, barriers to services created a field of structural and incidental obstacles for consumers to overcome. Furthermore, intersectional factors particular to each consumer (age, wealth, ability, marginalisations, privileges, etc.) mean that every person who experiences poor mental health will have a different capacity for initiating and sustaining their engagement with services (Brown, et al., 2016, p. 15; Bastos, et al., 2019, p. 210; Byrow, et al., 2020). Due to this, marked variations across consumer experiences are to be expected. Some people will get lucky and have a relatively smooth experience of accessing services. Meanwhile, others will encounter insurmountable barriers that exclude them from engaging services altogether. Therefore, in the third round of focus groups the research team sought participant's perspectives of their overall experience of accessing services in the ACT. Alongside this, we also sought feedback on the changes that participants wanted to see made to improve the system.

1. Overall experience of engaging with the system

In the third round of focus groups we asked participants to think of a word or phrase that they would use to describe their experience of engaging with the system over the past two years. The purpose of this exercise was to encourage participants to summarise their recent experiences, discuss the reasons for these sentiments, and through this identify any emergent themes or issues. Following these discussions, transcripts were prepared and coded for sentiment and salient phrasing. Responses were organised into three categories: positive, mixed, and negative. We found that participants reported predominantly negative sentiments with mixed and positive sentiment being significantly less frequent.

It bears noting that, due to the limitations of the project and the nature of this particular focus group exercise, the sentiments expressed by participants cannot be generalised as being representative of the wider community in the ACT. For instance, the sparsity of positive sentiment from participants may be a byproduct of self-selection bias in the recruitment process for the focus groups. That is, consumers with unambiguously positive experiences of engaging with the system in the past two years may have been less motivated to participate in the project than consumers with mixed or negative experiences. Consequently, the sentiments detailed in this section can only be taken as indicative of the sentiments of those participants who participated in the third round of the focus groups. This section should therefore not be used as a basis for making generalisations about the distribution of consumer sentiment towards services and the system. Given this limitation, the sentiment analysis in this section focuses on the aspects and features of services and the system that participants attached their sentiments to. In this way, the exercise and its analysis serves a means for identifying encounters and processes that were prominent for participants when they explained why they chose the words and phrases they did when describing their overall experience of the system.

1.1 Positive

The positive sentiments reported by participants included the following descriptors: "*adequate*", "*okay*", "*lucky*", "*very good*", and "*really good*". It bears observing that the words and phrases utilised by participants to describe their positive experiences were not always strong, such as "very" or "really" good, but rather muted or contingent, such as "adequate", "okay" or "lucky". One participant who described their experience in unambiguously positive terms said:

> *I thankfully was able to access psychology through my education provider for free and that's been very, very good. I've had a really good experience of that service. And then also, remote access to a peer worker which has also been a really good experience.*

Similarly, another participant described their experience of the past two years as: "*Adequate, I have in the last two years adequately been able to access the supports that I needed.*" Other participants who described their experiences positively caveated their feedback. For example, one participant acknowledged that their positive experience was due, in part, to their access to financial resources:

> *Mine's been okay. … I'm lucky. I can afford a proper psychiatrist. So, money drives a lot of the issues for people. So, my service has been okay.*

This sentiment was echoed by another participant who said, "*I feel very, very lucky in that I've had very good access to very good supports that have benefited me.*" In contrast, one participant had high praise for a service they had been able to access, but noted that this had been an exception in their past two years of accessing services:

> *I have had a positive experience with getting a psychologist, but that was through another service that was set up for me, and it was just instant … I've been working with* [them] *for the last year, and that's been probably one of the*

> *only positive experiences in the last two years of, you know, being able to get to services and maintain that.*

Few participants expressed unambiguously positive sentiments about their experience of engaging with the system over the past two years. The factors that participant feedback associated with positive experiences of engaging with the system were: the service being affordable relative to the participant's resources, the speed with which the participant was able to connect with and engage a service, and the quality of the services that they engaged with.

1.2 Mixed

The mixed sentiments reported by participants included the following descriptors: "*surface level*", "*superficial*", "*50/50*", "*partly satisfied*", and "*partially ok*". Sentiments that fell into the 'mixed' category primarily concerned participant experiences where a service had been successfully accessed, but aspects of the service provided, or how the service was delivered, fell below the participant's expectations. For example, one participant described having an overall positive experience with a service, but that communicating with the service had soured their experience:

> *It's been okay and they're happy to come to your home and check in regularly, but one of the particularities I have is picking up a call with no caller ID. Like this invokes a whole bunch of random emotions in me, I specifically instructed them 'Please do not do that'. And they're like, 'Oh, we cannot accommodate that request', and I'm like, 'Okay, I won't be picking up for call in that case'. … I've had some previous traumatic experiences with like no calling ID, harassment, that sort of thing.*

Alternately, other participants were appreciative of being able to access some services but felt limited in their options or let down by the system due to being unable to access other services. As one participant described:

> *I'm partly satisfied, it's partly ok. Just because of that NDIS, because it's in my NDIS funding. But I've got other things that I'm not satisfied with. You know that, like I want, I want to be able to, you know, have regular sessions with a psychiatrist*.

Another participant shared this sentiment and summarised their experiences succinctly when they stated that: "*I've had really bad experiences, and I've had really good experiences. So, 50/50 for both of those.*"

Prior to the third round of focus groups, the research team anticipated that a moderate amount of participants' experience over the past two years would likely fall into the ‘mixed’ category with participants using descriptors, phrases, and examples that conveyed both positive and negative sentiments, or conditional sentiments. However, this did not turn out to be the case. Moreover, due to the limited number of ‘mixed’ responses, in addition to the differing focuses of ‘mixed’ sentiment examples, it is difficult to draw out particular insights. If anything, the limited number of ‘mixed’ sentiments expressed by participants challenged the research teams’ expectations.

1.3 Negative

The negative sentiments reported by participants included the following descriptors: “*frustrating*”, “*limited*”, “*difficult*”, “*fragmented*”, “*piecemeal*”, “*disjointed*”, “*expensive*”, “*unsupportive*”, “*inconsistent*”, “*confusing*”, “*stigmatising*”, “*time-consuming*”, “*unfair*”, and “*woeful*”. Whereas the descriptors and phrases used by participants for positive and mixed sentiments were brief and limited, for negative sentiments, participants employed numerous and colourful terms to describe their holistic experience of the system over the past two years.

Negative sentiment among participants was far more common and detailed than for either positive or mixed sentiments. Negative descriptors such as “*frustrating*”, “*limited*”, “*expensive*” and “*difficult*” were commonly used, with “*fragmented*” and associated descriptors like “*piecemeal*”, and “*disjointed*” also being employed. Not all of these sentiment descriptors will be individually analysed in this section, however, we will discuss the most frequently employed terms and the aspects of services and the system that participants associated them with.

‘Frustration’ was the most common negative descriptor used by participants and it was applied to a range of contexts and experiences. One participant used ‘frustration’ to describe their experience of encountering extended wait times to access services:

> *I’m with another service, and it’s like the wait times are horrendous. I tried to go private, but that wasn’t, I wasn’t able to afford it when the appointment came up for me. And I just keep getting sort of tossed around to different, in different referrals, because they can’t, they don’t have the time. So yeah, I’m on another waitlist. So, it’s just frustrating.*

Likewise, another participant used ‘frustration’ to describe their experience of getting a referral from a GP:

> *I had to come back in two weeks’ time and give* [them] *some names after doing a lot of research and, you know, not easily finding, I supposed, any free services or bulk billing services. … It was just really frustrating. And I went*

> *back with a couple of names, and then I couldn't get on their list anyway. … it's just been a very frustrating process.*

'Frustration' was also linked to the financial cost of accessing services. For example, one participant described the difference they experienced between private and public services in terms of cost and quality of care:

> [I]*f you want to get good care, it's very expensive unfortunately. And just getting general care, particularly in the public health system still, for me, after the pandemic, could still remain pretty frustrating, because you're really not getting what you want … in my experience it is, it's frustrating, it's just hard, big, and it is expensive.*

Examples such as these reiterate the characterisation of barriers to services that emerged from the second round of focus groups. Namely, they demonstrate the discouragement and disincentivisation that arises from encountering multiple barriers, or having repeat experiences of friction, within the system.

'Limited' was an unexpected descriptor that arose with some frequency and it was used by participants in two ways. The first was to describe how they felt about their options as a consumer in the system. The second was to describe their experiences with the federal BAI program through which a person can receive a mental health care plan from a GP to receive a subsidy for the appointment costs of certain services (Thornley & Harris, 2021, p. 36).

Participants who described their experience over the past two years as feeling 'limited' described circumstances and situations in which they were encountering one or more barriers that restricted their service options. One participant succinctly summarised a group discussion that illustrates this well:

> [T]*he services we access are limited. We may only have a certain number of sessions, they may only be available at certain times. … So, there's a lot of these sorts of limitations that … in itself, is a barrier. It's harder to access good quality* [care] *if all your supports are limited in some way.*

This sentiment was echoed by a participant who reported struggling to access services due to not meeting the criteria to receive support from public service providers:

> [W]*hat I mean by that is having the experience of feeling like my existing supports were not enough, and … being told that, you know, I don't meet the criteria to access certain supports. … So, then being limited to the private system, and then the sort of, having to get into the private system and those other barriers of, you know, costs and accessibility.*

Another participant expressed similar concerns in the context of their experience of their choices being limited due to a lack of information, that is, of encountering service navigation barriers:

> [I]*t's really limited as to the information. That there's no list of psychiatrists, there's no list of, you know, GPs, that will prescribe. … there's just not a lot of information about who does what, and where to go and what to do.*

Likewise, 'limited' was used to describe the reduction of a participant's agency: "[W]*hen there's limited options, I feel less empowered because in some respects, I just have to take what's available and what's given to me.*"

While the BAI is a Commonwealth administered program, awareness of the sentiments and issues that participants report regarding this major pillar of service accessibility remains important for understanding the part it plays in the care pathways of ACT consumers. Participants who utilised mental health care plans under the BAI over the past two years used 'limited' to describe it in negative terms. For example, one participant said,

> *I find the ten sessions quite limiting as someone with an ongoing disorder. … That number of sessions doesn't really meet the needs that I have.*

Similarly, another described their experience in terms of the continuity of care:

> [T]*o me, continuity of care is the big one that … if you have a limited number of sessions, what is the next step afterwards? What is the exit process?*

This feedback emphasises the additional affordability barriers encountered by participants with intensive and/or long-term mental health support needs.

When describing their overall experiences of engaging with the system in terms of 'limitations' and of being or feeling 'limited', such feedback can be interpreted as suggesting the operation of barriers that are significant enough to not just frustrate a participant's engagement with services, but to actively reduce their options for care. Whether it is because a consumer is unable to find information regarding services (service navigation barriers), can't afford services (affordability barriers), or are ineligible for services (availability barriers), the term 'limited' carries notably negative connotations for the consumer experience of the system as a whole.

'Difficult' was used several times and participants used it in association with issues such as stigmatisation, service navigation, and service availability. One participant for example highlighted the negative experiences they had with a practitioner: "*It's difficult because I … don't get on with some of them. …* [they were] *horrible and judgemental and stressed me out.*" Meanwhile, other participants described navigating the system as being 'difficult', for example, one participant found that:

“*The lack of coordination between services … Finding that link between the federally supported services and the ACT one has been difficult.*” Likewise, another participant described trying to access counselling: “*I couldn’t just regularly see a counsellor except if I was in crisis where they were in the hospital or something. But yeah, so it’s difficult*”.

Lastly, when some participants were prompted about their holistic experiences over the past two years, they described their experiences with reference to encountering service navigation barriers for which they employed a cluster of closely associated words: “*disjointedness*”, “*fragmented*”, “*piecemeal*”, and “*cluttered*”. One participant stated that they felt: “[L]*ike the information on navigating mental health supports is cluttered, and pathways and the experience of treatment and diagnosis.*” Likewise, another participant described how:

> *I find I can capably get access to services that support some of my needs, but not others. … and I can’t find other supports for other sources of distress. So, I guess for me there’s a sort of disjointedness.*

Another participant recounted how their: “[E]*xperience is also fragmented … because of the, what I have found to be, the lack of options in the ACT.*” As with previously discussed negative descriptors, such sentiments conveyed by participants suggest that there is an unacceptable degree of friction in the system. Moreover, such friction would appear to be especially apparent for consumers who have fewer resources available for initiating and sustaining their engagement with services.

The negative sentiments articulated by participants point towards multiple barriers that combined to create a very poor consumer experience. Negative sentiment was tied to reports of difficulties with navigating the system, limited options, and the cost of services. Additionally, many of these reported problems implied affordability barriers arising from both up-front and long-term cumulative costs. This feedback suggests that consumers who encountered affordability barriers over the past two years may be more likely to have had negative experiences with the system and perhaps to hold negative sentiments about it. From this, future research might consider exploring the relationships between affordability barries, consumer sentiment and consumer dis-/engagement with services.

Overall experiences summary

The purpose of this exercise in the third round of focus groups was to prompt participants to reflect on their experiences over the past two years, gauge their sentiment, and to highlight the facets of the system that participants associated with these sentiments. The responses of participants to this exercise suggest that there are many ‘pain points’ for participants in the system and that these issues are linked to both material and holistic barriers. In particular, participants associated their negative sentiment with service navigation, affordability, and availability barriers.

The overall experiences of participants indicates that both the difficulty of navigating the system and increasingly unaffordable services create significant friction that consumers must overcome to access services (Chandra, 2024, pp. 19-24; RACGP, 2024, pp. 11, 35). Integrated with the framework of material and holistic barriers, it is fair to propose that there are multiple barriers in the system that reduce consumers’ capacity to initiate and sustain their engagement with services (Chandra, 2024, pp. 19-24). Furthermore, with the ongoing housing crisis and cost-of-living pressures, consumers are already experiencing multiple social stressors that both increase the need to access services and decrease the resources they have available to do so (ACOSS, 2024; RACGP, 2024, pp. 11, 14, 17, 35). The barriers in the system described by participants are certainly compounded by these external factors and as such, they serve to further discourage and disincentivise consumers from engaging with services.

More needs to be done to support consumers in the ACT by reducing material and holistic barriers, especially for people with intensive and/or ongoing needs as well as for those who encounter affordability barriers (ACOSS, 2024; RACGP, 2024, pp. 11, 14, 35; Chandra, 2024, pp. 19-24; Looi, et al., 2024). It is on this point then that we will now review participant feedback regarding the changes that participants recommend for improving the system.

2. Improving the system

For the final discussion of the third round focus groups we asked participants to reflect on their experiences over the past two years and to make recommendations about improvements to the system that they would like to see to reduce barriers in the system. When introducing this discussion to the focus groups, we recommended that participants include both Commonwealth and Territory level services, programs and features in their recommendations. The reason for this decision was that Commonwealth programs such as the BAI play an important role in the ACT system even when a participant is unable to utilise the program. As such, in the feedback that follows some of the recommendations proposed by participants require action across both Commonwealth and Territory levels of government. This feedback is important for the ACT mental health sector, policy makers and the public alike because it identifies issues that require concerted effort from ACT communities, non-government organisations, policy bodies and political representatives if they are to be addressed.

Discussions for this part of the third round were organised in relation to the two categories of barriers identified by participants in the first round of focus groups: holistic accessibility barriers (quality of care, interpersonal interaction and service navigation) and material accessibility barriers (service availability and affordability). Feedback on these topics were marked by a diversity of potential improvements and interventions ranging from the local and specific to national and systemic. In this regard, the recommendations present a spread of possibilities that can be actioned by different agents and coalitions throughout the mental health sector and across the ACT.

The public funding of services was a recurring discussion point insofar as participants recognised that many of the improvements they proposed would require additional investments and resourcing. To the extent that this is an assumed aspect of the proposed improvements, funding will not be treated as a separate topic of discussion except where it was discussed as a specific issue in its own right.

2.1 Improving the holistic accessibility of services

Improvements to the holistic accessibility of services attracted a lot of feedback and addressed quality of care, interpersonal interaction and service navigation barriers. As noted in earlier discussions, holistic accessibility is an important issue for consumers. Trust, ease of access and competent care support a consumer’s ability to initiate and sustain their engagement with the system (Brown, et al., 2016, p. 16; Birkhäuer, et al., 2017; Whittle, et al., 2018, p. 87; Laugharne & Priebe, 2006, pp. 849-850; Byrow, et al., 2022, pp. 14-15; Kavanagh, et al., 2023, p. 18). In this context, participants highlighted the emotional safety and competency of mental health practitioners and general staff as well as the continuity of care between service providers as key areas where improvements can be made to the system. Interpersonal interaction barriers were frequently cited by participants during discussions of their recommendations. Specific interventions that participants requested included implementation of peer-led and lived-experience services and programs as well as improved standards of training service staff engaged in front-line work and greater accountability of service providers.

Participants saw peer-led and lived-experience services and programs as a way to improve the holistic accessibility of both specific services and the system as a whole. For example, one participant expressed their high regard for peer-led models of care:

> *I think the peer model is heavily underestimated and heavily underfunded. I think it’s proven to be highly effective and connect more … I think the peer*

> *model brings everyone together and I think it has been … for me anyways, more holistic than most doctors.*

Another participant highlighted what they saw as the potential of such approaches to services:

> *I echo the sentiment of greater peer support to help navigate and negotiate the system. This is particularly important for teens and young adults who tend to need a balance between guidance and independence.*

Participants described a range of peer-led programs and services that they would like to see implemented and expanded upon in the system. These included services that could be provided at emergency departments, standalone services to assist with service navigation and advocacy, as well as increased funding for peer-led specialist community programs. Regarding peer-led support in the emergency department, one participant described their experiences and said that they would like to see:

> [S]*omebody there who is, particularly when presenting to the emergency department, or some sort of, having someone to sort of be with you because they’re* [the staff] *are so busy*.

Another participant identified community advocacy services as another kind of peer-led and lived-experience program that they wanted to see: “*I guess having like a community level network, peer or ambassadors, whatever you want to call it, … just to advocate.*”

Community provided programs that utilised peer workers and peer-led, lived-experience models of care were also identified and proposed as ways to improve the system. For example, one participant identified the community group Borderline Personality Disorder Awareness (BPD Awareness) as a peer-led group that they had had positive experiences with. This participant wanted to see better: “[F]*unding for places, I don’t know who’s in the ACT, but places like BPD Awareness. … funding for the groups that utilise, you know, peer support and skill.*” Likewise, another participant described how they saw peer-led programs and community groups as a way to provide specialised support that might otherwise fall beyond the scope of more formal services:

> *So, this is more for the holistic side of things. So, looking at social groups … something that starts more centralised but peer-led services where possible. … So, for people interested in cooking, there might be a peer with lived experience that runs cooking groups, someone who with lived experience who is into swimming, might, you know, organise that*.

This feedback indicates that at least some participants have had very positive experiences with peer-led and lived-experience models of care. While it is beyond the capacity of this Report to argue the evidentiary case for peer-led community services, programs and groups, it can be proposed that this feedback should encourage further research into the piloting and development of such service and program models.

The other major area of improvement for holistic accessibility identified by participants were the standards of services. Though a broad term, participants proposed several ways to improve the standards of services. These recommendations included the following:

- service safety and competency auditing;
- upskilling programs for staff moving into mental health roles; and,
- higher training standards for mental health relevant qualifications.

Some participants recommended additional public auditing of service providers. One participant summarised the underlying motivation for this recommendation: "[W]*e've all been through the meat grinder, we know who can do that work and who can't*". Which is to say, participants who have had negative experiences want to avoid similar future experiences and auditing of service providers may be one way to achieve this. One participant stated this explicitly: "[M]*y idea would be to have a set of standards that a hospital would have to achieve to earn it, like, you know, 'the star of being mentally safe'*". Likewise, another participant expressed that:

> [S]*taff working in programs or services need to be monitored, either need to be upskilled or need to be monitored better so that they're providing safe services and supports*.

Evidently, participants want to be able to know that the services they are accessing have met certain standards and have a record of providing professional and high quality care.

Upskilling, expanded qualification requirements, and specialisation in the care of specific mental health conditions were requested for all levels of staff involved in the provision of services whether public or private. Participants placed a strong emphasis on the unique and complex nature of mental health care as a care-practice that depends as much on the interpersonal interactions through which it is conducted as it does on the clinical process of diagnosis, prescription, and treatment (Knaak, 2017, p. 113). As one participant stated: "[Y]*ou can have the most academically qualified, medical professional …* [b]*ut if they're lacking sensitivity, then it is still a big problem.*" Participants recognised that ongoing training was a challenging process to implement, but they nonetheless stressed its importance for ensuring high quality mental health care:

> *The training of empathy and culture, and all those important sorts of things that you need to develop, given the sense of nature, of the system, and the trauma and triggers, and so on. So, you know,* [you need a] *great deal of empathy, and that comes with, you know, continuous training, I guess, of staff.*

Another facet that participants identified was the lack of support for health workers undertaking front-line and face-to-face work with consumers. Specifically, participants highlighted the need for additional training so that health workers are equipped to handle complex situations and so that consumers can trust that the staff they're interacting with are skilled and empathetic. As one participant stated:

> *Lower skilled workers that are working one on one, especially if they're going to be put in mental health, which they predominantly are, the mental health or aged care, they should have that, more specialised training, because they are doing a lot of the work.*

Throughout this part of the focus groups, the clear theme that emerged from participants was the need for improvements to *how* mental health care is provided. While funding constraints and federal policy may place limits on the scope of the improvements that can be made in this area of the system (Thornley & Harris, 2021, pp. 50-54; Wang, et al., 2024, p. 5), it is nonetheless an area in which public and private service providers have a crucial role to play (Knaak, et al., 2017, pp. 12-13). For instance, all service providers are able to ensure that their workplace cultures uphold empathetic and professional interpersonal standards of care. Though the piloting and introduction of peer-led services and programs is a more complex goal to implement, service providers are nonetheless able to improve their engagement with consumers by creating avenues for direct feedback and ensuring safe and empathetic interpersonal interaction (Knaak, et al., 2017, p. 13).

2.2 Improving the availability of services

Discussions about improving the availability of services included two senses of the term 'available' that are both important aspects of service provision. That is, *what* services are present in an area and, *how* services in an area are accessed (Whittle, 2018, pp. 84-96; van Gaans & Dent, 2018, pp. 3, 10, 12). For instance, a service that does not exist in an area cannot be accessed and it is therefore 'unavailable'. Yet, a service that exists in an area may be 'inaccessible' due to factors such as cost, capacity, or other holistic barriers even though it is 'available' in the sense of 'being present in an area' (van Gaans & Dent, 2018, pp. 10, 12; RACGP, 2024, pp. 3, 7). The improvements that participants recommended addressed both aspects of service availability in the system.

Participants proposed both novel local programs as well as changes to Commonwealth programs. The specific improvements requested by participants regarding the availability of services in the ACT included:

- Expanding the accessibility of the NDIS to provide coverage for psycho-social disabilities that require ongoing psychological and/or psychiatric care;
- Reinstating the twenty session per year mental health care plans under the BAI;
- Community spaces that facilitate social inclusion and positive psychosocial interaction;
- Piloting and expanding the range of alternative therapies; and
- The development of services that assist consumers with managing information, coordinating care, and navigating services.

Commonwealth programs such as the BAI and NDIS were both identified by participants as requiring improvements. For the BAI, consumers in the ACT were impacted by the Albanese government's decision in December 2022 (Worthington, 12 December 2022) to return the COVID-19 era extensions to the number of annual subsidised sessions from twenty back down to ten. As one participant stated:

> [E]*ight sessions, ten sessions,* [are] *clearly dumb numbers. Like you'd need twelve to have one a month, to have two a month for six months, or something, and that clearly should be the acceptable minimum for most people in their circumstances. … I think to me, continuity of care is the big one that …* [i]*f you have a limited number of sessions, what is the next step afterwards?*

Other participants expressed similar concerns regarding the BAI with one stating that: "*I'd like to have more than eight free sessions with mental treatment. … I could do with double that.*" Another participant said that there needs to be:

> [A] *different set of options for people who have an ongoing, like a chronic condition or disorder, versus people that are experiencing more episodic distress. Because I find the ten sessions quite limiting as someone with an ongoing disorder.*

Likewise, one participant pointed out some of the practical problems with the BAI that could be addressed by returning to the twenty-sessions per year model:

> *If you end up having to link in with a new psychologist, and they just don't work well, you give them a couple of trials. That's a few of your sessions gone for the year. You then have to go find someone else* [and] *it might be the same story, you've used up all these sessions just trying to link in, connect with someone, and it's just not sufficient to get through the year.*

Should the re-elected Labor government stay true to its pledge to reinstate the twenty-sessions per year model, the Network looks forward to tracking the impact of this change for consumers' experience of the system in the coming years.

Participants made similar proposals for improving the NDIS For example, participants proposed the expansion of the NDIS to include more people with psychosocial disabilities and/or comorbid chronic conditions. One participant explained why they want to see greater ease of access to the NDIS program for consumers:

> [W]*hen the NDIS first came about I did apply and I was told 'No, I couldn't, that I didn't have a temporary disability.' And I'm like, you know, shouldn't ADHD* [Attention Deficit Hyperactivity Disorder]*, complex trauma, PTSD, anxiety, depression be enough? But no, it wasn't at the time.*

This sentiment was expanded upon by another participant who stated that:

> *I'd improve the quality of care for the mental health services and supports by increasing access to the NDIS for more people with psychiatric illnesses. …* [I]*t's extremely, famously hard for people who are actually applying to get on* [the NDIS] *and I think that something the ACT government, or similar, could do is advocate for more people with mental illnesses to get on* [the NDIS].

Participants also attributed a 'displacement effect' to the NDIS in which local community spaces and programs have become unavailable due to the redirection of public funding. One participant described how they have:

> [N]*oticed a lack of services since the NDIS came, and an issue, sort of part of that,* [is] *a lack of social opportunities in the community. There used to be things* [like] *… a swimming group that you could do by, you know, joining a community group. But that's also sort of, everything is tied up now with NDIS packages, and if you're not, you know, if you're not unwell enough to be eligible, then I think there's a lack of social supports.*

Beyond the NDIS, community services and supports were other areas where participants saw room for improvement. Participant recommendations for improved community supports covered a range of services, programs and therapies. This included the expansion of alternative interpersonal and clinical therapies such as "*equine therapies*", "*ketamine treatment*" and wider availability of cannabis derived medicines. Public services that assisted with service navigation and information management were also proposed:

> *I wish something existed which was like one* [phone] *number that you could call and it was staffed on the other end by trained … people like us with lived experience that have gone through this system where you could ring and say,*

> *you know, 'hey, I've got this going on' so, for instance, I need a DBT* [Dialectical Behavioural Therapy] *service … it would just be really great to be able to access all of that knowledge in one spot.*

Another participant suggested the creation of: "[A] *central hub where someone is employed, presumably in the health department, to maintain a list of all these services and what they do*". Participants also suggested community supports that:

> [C]*reated community events and community spaces that are for people like ourselves. But it's not there because you have this condition. It's 'this is an open event for you to come* [to]'.

The importance of such supports according to one participant was that they provided "*engagement to get motivated and hear similar, like stories.*" For this participant: "*Groups, community* [activities that] *spend time not necessarily talking about illnesses and conditions*" were also a part of the mental health recovery process, not just clinical and medicinal interventions. Here, participants stressed the importance of social inclusion as a key part of care, support and recovery. Without such avenues for maintaining one's mental health and finding peer support in times of distress, consumers can find themselves without options for support outside of the primary and acute health system. In this area, more needs to be done in the ACT to better support consumers in the community outside of primary and acute service contexts. In this regard, it is apparent that existing and new community services, programs and groups have the potential to play an important role in the future of the system.

2.3 Improving the affordability of services

Recommendations about improving the affordability of services was general and consistent across the focus groups. Participants strongly agreed that significant increases in the public funding of the system and services needed to be made across the board by both Commonwealth and Territory governments. Beyond this endorsement of increased general public investment though, participants identified three priority areas where they recommended increased public investment:

- expanding the ACT mental health workforce;
- increased availability of GP bulk billing services; and
- increased public welfare payment rates.

Discussions around the affordability of services were brief in comparison to other topics. This reflected the consensus among participants that more general public investment in the mental health sector, both nationally and locally, is the key problem to be addressed by Commonwealth and Territory governments. Due to this, the position and length of this section in the document should not be taken as an indication that the affordability of services is a low priority for consumers (ACOSS, 2024, pp. 12-14; Chandra, 2024, pp. 19).

Participants proposed that increased public investment in the system and services was a direct way to improve the affordability of services for consumers. One participant stated that they wanted to see more investment in: "[C]*ommunity support, including the peer variety, integrating mental health services into primary care settings*." Another participant linked this investment directly to government policy priorities: "[I]*t comes down to the government prioritising it. I mean, we all pay … if that was in their priority, then they would budget more money for it.*" A separate participant echoed this sentiment: "[A]*s far as affordability goes, yeah, I think it starts with the government*". Participants recommended increased public investment not just as a means of addressing current service demand, but also as a means of preventing future system load. As one participant stated:

> [I]*'m a strong believer of early intervention. So, if you just start with that from a young age and invest in it then, then you just save so much more long term.*

Certainly, if the present service demand and budgetary issues facing Canberra Health Services are anything to go by, more will need to be done, and soon, to relieve primary and acute service demand under circumstances where the social drivers of poor mental health are likely to worsen rather than improve.

Notably, participants tended to refer to 'government' in general terms and did not regularly distinguish between the ACT or Commonwealth governments. This being said, some participants' proposals had a clear focus on Commonwealth level policy and funding. For example, one participant specified Medicare in their recommendation: "[T]*hey need to expand Medicare, like that's the government mechanism, and to make healthcare affordable in our country.*" Likewise, another participant recommended private health insurance reform as a priority:

> *I'd like to put* [forward] *the abolition of private health funds. If everyone who paid the money into private health funds paid it into public health care, and had to use the same system as the rest of us use,* [then] *we might actually get some rich people advocating for decent health care.*

Feedback such as this suggests, at least, a dissatisfaction among participants with the level of direct public investment in the national system by the Commonwealth government. This sentiment could be extended as well to the ACT government. However, follow up questions concerning this were not asked of participants in these focus groups.

Participant feedback on improving the affordability of services included several recommendations for expanding the ACT mental health workforce. Participants saw addressing issues such as understaffing as an important aspect of improving the quality of mental health care as well as the provision of subsidised services. As one participant stated:

> [T]*he free services have to be added to, like doctors. They just need more doctors, more services to give to people, because obviously there's a shortage, like a huge shortage.*

Similarly, other participants recommended: "[I]*ncreasing pay for people who work in the sector*" and providing "*better incentives … it's really high stress, like, it's really very challenging.*" The problem as another participant saw it was that there needed to be:

> [I]*ncreased staffing and funding … we need more nurses. We need incentives for them to enter these degrees in the first place. We need it to be a good career and rewarding career. Rather than, you know, there being this culture of, you know, a lot of burnout.*

Such recommendations reflect broader ongoing policy discussions and concerns regarding major issues in the mental health workforce both within the ACT and across Australia more generally (CHN, 2021, pp. 107-112; OMHW, 2023; RANZCP, 2024; Loui, et al., 2024). Notably, these issues cut across Commonwealth and Territory government responsibilities, making the implementation of such improvements an issue in and of itself.

Bulk billing was another key where participants made recommendations for improving the system. Due to the role of GPs in providing access to both public and private services (van Gaans & Dent, 2018, p. 10; RACGP, 2024, pp. 3-5, 16, 35), participants saw the rise of GP appointment costs and the reduction in the availability of bulk billing appointments as a critical problem (Black Dog Institute, 2024; RACGP, 2024, pp. 7, 14). One participant recommended that "*no matter what the GP charge is, like, if you're going to get a mental health plan, that appointment should be free.*" Alternatively, another participant stated that "*in the ACT, there should be some provision made where you have a ratio of bulk billing*". As one participant recommended, they wanted to see:

> [M]*ore transparency around payment options. It'd be nice to know exactly how much I can expect to spend trying to achieve a particular result. What access is there to financial assistance that I can get? Like if there are payment plans accessible to me; if there are charities who can help me if I'm in a financial hardship again?*

Because GPs often play a coordinating role when it comes to an consumer’s mental health care (Thomas & Harris, 2021, p. 22; RACGP, 2024, pp. 16, 35), any increase in costs associated with accessing a GP, or a decrease in the availability of bulk billing clinics, directly affects the affordability of mental health care for consumers (Chandra, 2023, p. 26; Black Dog Institute, 2024; RACGP, 2024, p. 14). Moreover, because the Medicare system is, for consumers, a rebate system, appointments still require consumers to be able to meet the full upfront cost of accessing a service (van Gaans & Dent, 2018, p. 10; Wang, et al., 2022). The terrible reality for many consumers is that these upfront costs alone are sufficient to exclude them from the system entirely. In such circumstances, and where bulk billing services are few or non-existent, consumers are left with few choices and will forgo accessing services altogether (Wang, et al., 2022, p. 2; RACGP, 2024, pp. 14, 35).

Lastly, and tied into the issues already discussed in relation to bulk billing, participants recommended increasing public welfare payment rates as a means of supporting consumers to be able to afford to access services. Public concerns regarding the rates of various welfare payments are well documented (van Gaans & Dent, 2018, p. 12; ACOSS, 2024; Wang, et al., 2024, p. 5), and these issues were reflected in participant feedback. As one participant observed:

> [W]*e get this CPI* [consumer price index] *thing … but it gets wiped out a few weeks later … So,* [an] *actual increase in the pension. You know, it’s due now.*

Likewise other participants highlighted the DSP as a specific payment that also needs to be raised: “*increasing the disability pension, subsidies for access to mental health services or public health services*”, and “*increase the dole, increase the DSP, and everything actually improves overall.*” With the cascading consequences of affordability barriers documented earlier in this report, both Commonwealth and Territory governments must make it a policy priority to ensure that Australians have access to services that are affordable for all. As is well known, if investments aren’t made to improve the affordability of services *and* address social determinants of poor mental health and mental illness, then the costs *will* be borne elsewhere and at far greater expense to both consumers and government.

Summary of recommendations to improve the system

Although affordability barriers received the least amount of direct attention across the focus groups, the unaffordability of services was an issue that shadowed every discussion. Most of the recommendations that participants put forward for improving the system were directly or indirectly related to addressing issues that affected the affordability of accessing services. Improvements to holistic barriers frequently focused on issues relating to the mental health workforce such as understaffing, insufficient training as well as poor workplace conditions and unrewarding career prospects. Likewise, improvements to availability barriers were concerned with reviving public community spaces and reducing the resource burden placed on individual consumers to navigate the system. Lastly, affordability barriers raised the issue of service unaffordability most directly with the declining accessibility of bulk billing, inadequate welfare support, the cost of living and the exclusion of mental health supports from the NDIS being the salient concerns that participants want to see addressed.

All of these recommendations reflect structural issues in the system that are being experienced by participants as barriers to services. Problems in the mental health workforce decrease the quality of services provided and reduces service accessibili through insufficient capacity. As well, problems with the funding of public community services, programs and groups, excludes and isolates consumers from social and support networks. Furthermore, problems with the rate of welfare payments and the exclusivity of vital public programs applies pressure to consumers across the board and amplifies the negative consequences of all other issues that they might encounter.

Responding to participants’ recommendations for improving the system requires increased public investment from both Commonwealth and Territory governments. Not only does more need to be done to ensure that services are properly funded to fulfil their purpose, the social determinants of mental illness such as housing insecurity, economic marginalisation and social exclusion also need to be addressed.

Obviously, the implementation of these recommendations is subject to bureaucratic and partisan political considerations at both the Commonwealth and Territory levels of government. However, such factors and the political challenges they entail, do not negate participants’ desire to see these recommendations implemented. The desire for better a system exists and it is the responsibility of the Territory government, public service, and the community sector to work together in good faith with to bring about such improvements. Should such improvements require Commonwealth level action and reform, then it is upon all of us to build the coalitions necessary to advance these policy priorities.

Report Summary

While this Report and its findings are the primary outcome of the project, the process by which it was produced also merits comment. By ensuring that participant feedback meaningfully directed the focus of the project's investigation, participants directed attention to the barriers that are affecting them the most and, through this, they revealed the manifold and compounding ways that these barriers can negatively affect consumers. This approach demonstrates that consumer research can be more than just a transaction of information between consumers and researchers. Co-producing the project with consumers not only expanded the diversity of perspectives contributing to the Network's advocacy, it also strengthened our relationship with ACT consumers.

Turning then to the substance of this Report, the feedback from the focus groups produced a range of insights into how we understand barriers, the process of accessing services, and recommendations for improving the system. Participants advanced our understanding of barriers by identifying a range of material and holistic barriers and describing their interrelations, dynamics and consequences.

Concerning material barriers, many participants described their effects in terms of either/or conditions: they either could or could not afford to access a service or attend an unavailable service. Yet the experiences of other participants also showed how consumers work to navigate material barriers to the best of their capacities, even though these barriers pushed them to travel further, pay more and/or wait longer for services. This was particularly evident with participants who reported rationing their subsidised psychology sessions or travelling interstate for services.

In contrast, participants' descriptions of holistic barriers indicated that they tended to have discouraging and disincentivising effects which reduced their capacity to initiate and sustain their engagement with services. In some cases, participants reported specific harms and trauma as a result of encountering holistic barriers, particularly with regards to poor quality care. Notably, for some participants, encountering holistic barriers damaged their trust and led them to disengage from services.

Importantly, participant experiences demonstrated that material and holistic barriers overlap with each other and the consequences of encountering them can compound each other, both the short and long term. Furthermore, participants produced an account of service navigation barriers that revealed their multilayered causes, cumulative effects and the complexities that policy makers face in working to improve the navigability of the system.

Regarding the process of accessing services, participants' descriptions of the complexity of engaging with services revealed how friction within the system reduces consumers' capacity to sustain their efforts. These discussions also indicated that solutions to these issues will require policy makers and service providers will need to collaborate to reduce the administrative burdens placed on consumers and improve the navigability of the system.

In terms of improving the system, participants proposed a raft of recommendations that can be pursued to reduce barriers and thereby alleviate the burdens placed on consumers by the system. Service affordability, quality of care and service navigability were key areas that participants identified as requiring interventions from both Commonwealth and Territory governments.

Participants recommended increased public investment in the system and services by both Commonwealth and Territory governments to meaningfully reduce the affordability barriers that exclude consumers from accessing services. We welcome the re-elected Labor government's pledges to increase public health and mental health investment. However, other structural issues affecting the affordability of services will require further intervention if our healthcare system is to serve all Australians equitably (Guha, 12 April 2025). For example, ongoing uncertainty around the availability and status of psychosocial supports in the NDIS continues to exclude consumers from accessing vital long-term supports and services.

Noting these issues, in the ACT the returning Barr government faces the challenge of identifying gaps in the system and making targeted investments to bridge them in the present and cover them in future. Here, investing in the strengths of existing public and community services must be considered as a crucial component to any such strategy. To this point, community service organisations can play a significant role by addressing specific needs in the local community, providing early intervention supports, promoting social inclusion and nurturing local expertise. Through this, community services can complement clinical and acute services by offering free or low-cost options to consumers whose circumstances may be better supported through peer-led programs or groups. However, the capacity of community services and organisations to fulfill this roll is contingent on the direct funding and indirect supports that the ACT government is able and willing to provide.

With respect to improving the quality of care provided by services, participants recommended that front line health workers need better workplace support to be able to provide effective and compassionate care. In this, participants also saw an important role for peer-led services and peer-workers to help consumers connect with services and recover in community. Participants clearly appreciated the complexity of the service environments and empathised with the often-difficult working conditions faced by frontline health care workers. They therefore recommended additional investment in the mental health workforce to increase staff capacity, retention and improved workplace conditions.

Participants also stressed the need for improved system navigability, clearer service pathways and better consumer informational support. While this set of barriers proved to be complex, participants recommended several useful local interventions that can be considered. Peer-led service navigation programs could be implemented to assist consumers with complex and comorbid conditions with connecting to multiple services. As well, comprehensive service mapping can be undertaken to ensure that primary health care and service providers have access to up to date and relevant resources to facilitate consumer access to services. Lastly, consideration should be given to initiatives that strengthen inter-service pathways between private, public and non-government service providers.

Participant feedback from the focus groups demonstrates a pressing need for Territory-level policy initiatives and investment to compensate for broader issues that affect both the social determinants of mental illness and the structures that sustain our national mental health workforce. In taking up these challenges, policy makers and service providers need to consider how the process of accessing services can be organised to reduce barriers to services and facilitate consumer engagement with the system. At the same time, community service organisations represent an underleveraged sector that can, with additional public resourcing and support, expand the scope of their services, curate ACT-specific knowledge, and bridge vital gaps between public and private services.

This Report reaffirms many of the known challenges that consumers face when accessing services: the process is lengthy; imposes cumulative financial costs; involves repetitive and time intensive administrative tasks; and bears the risk of serious long-term harms. For some consumers, the system does offer appropriate pathways and can provide effective care that leads to positive outcomes. Yet, for others, the confluences of limited-service access, insufficient supports, financial stress and marginalisation create chronic instability wherein meaningful long-term recovery is improbably if not impossible. Critically, it is consumers with the fewest resources and most complex needs who are most disadvantaged by this system and who, if they are not entirely excluded, are the most likely to become trapped in this vicious cycle.

In the final summary, the system should not reinforce and perpetuate the problems it is intended to solve and consumers who engage with the system should not be left materially, physically or mentally worse off as a result of seeking help. Given this, it is evident that significant work is required to rectify this situation and improve the system. This being said, there is great opportunity here for change and, as participants’ recommendations show, we do not lack for options. A better system is within our power to achieve, we need only the resources and public commitment to realise it.

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