National Report 2022

Reflections on a journey of change

Personal experiences of a decade of reform activity in mental health



Australian Government National Mental Health Commission

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Joint foreword

As a contribution to the National Mental Health Commission's 10-year anniversary, we present a special companion to the National Report 2022—Reflections on a journey of change.

This report draws together reflections on how far the national mental health and suicide prevention systems have come over the past 10 years and helps illuminate the impacts people have experienced.

The amplification of the voices of lived and living experience, their families, carers and kin are at the heart of our work, as we seek to facilitate and promote their experience and expertise together with those directly providing services.

These reflections occur in the context of Australia continuing to grapple with the impact of conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping daily life. Together with recent disasters, including the COVID-19 pandemic, floods, bushfires and droughts, and alongside cost-of-living pressures, these are having a direct bearing on the mental health, and social and emotional wellbeing of people living in Australia.

Behind the creation of the Commission in 2012, is a powerful living legacy of more than 50 years of advocacy from the mental health consumer and carer movements, seeking reform to the way we think of, care for and partner with people experiencing mental health challenges.

The past 10 years has already seen a significant level of activity and change in Australia's mental health and suicide prevention systems, with mental health increasingly part of our national conversation. However, as this report attests, there is still a long way to go to build person-centred systems that harness a suite of services which are available (accessible and affordable), integrated, localised, and accountable for all people living in Australia.

The Commission is committed to driving transformational change. Our purpose is clear – develop, collect and analyse research, data and information to monitor and

report on improvements to the systems; inform a broad perspective of mental health and suicide prevention policy and reform; connect with a diversity of stakeholders, provide independent advice to improve mental health services and support, and release and promote evidence-based information, data, research, and best practices to support better treatment, support, and holistic care outcomes.

The ongoing need for system change remains urgent. This report supports us in promoting a person-centred approach to engage and connect people with lived and living experience, their families, carers, kin and communities in building an Australia where all people can lead contributing lives in socially and economically thriving communities.



Christine Morgan Chief Executive Officer National Mental Health Commission



Professor Ngiare Brown Chair National Mental Health Commission

Introduction setting the scene

The National Mental Health Commission (the Commission) was established in 2012. Priority activities for the Commission include engaging with all the different stakeholders in the mental health and suicide prevention systems, and reporting annually on the progress of reform. In 2022, after 10 years of Commission activity, it is time to pause and reflect on the experience of change.

The final report of the Productivity Commission Inquiry into Mental Health (2020)1 noted that substantial mental health reform activities had been undertaken over the previous few years, moving towards a more person-centred and flexible mental health system. Change is happening in mental health every day. But it can take many years before change at a decision-making level is experienced at the touch points between service users and their families and service providers.

Most mental health service planning focuses on developing systems and services to address population-level needs. Service users, on the other hand, look at the system from a more immediate and personal perspective. They look at what happened when they needed help. To interpret the progress of reform, we must understand how reform is changing the experience of service users and their families, communities and service providers.



About this report

From the Commission's first meeting, a commitment was made to always have people at the heart of what we do:

We need to provide 'a complete picture' of what is happening and closely monitor and evaluate change. Behind every bit of data is a part of a person's story. It is often the only voice that a person has. Data doesn't always show the important work being carried out in the community or by private providers or the important role that families, support people and peer workers provide. It doesn't tell us if people's lives are improving, whether they are being treated with respect, or whether we have got the balance right in where we spend money.²

In 2022, the Commission collected reflections on the experience of change from people involved at the frontline of the mental health and suicide prevention systems. This report explores the impact of reform through the experience of consumers, carers, families, support people and service providers. This collection of stories provides an experience-informed lens through which to understand the impact of change, linking the experience of the past 10 years with a vision for mental health and suicide prevention for the next 10 years.

Method

We adopted an interpretive approach to explore individual experiences, informed by the principles of Interpretative Phenomenological Analysis. Sample sizes in this approach are small, and we selected participants for their experience of the topic being investigated.³

For the Reflections on a Journey of Change project, we identified 32 participants from people who had worked with or contributed to Commission activities but whose voices were not usually at the forefront of published reports.

A total of 21 people had an individual conversation about change with a Commission representative. For this report, an open conversational approach was used to allow space for participants to explore any issue of importance to them. The broad topic of conversation was their experience of changes in the mental health system. Three key questions provided a frame for reflection:

- What has changed?
- How has this affected you or the people you represent?
- What still needs to change?

The personal experiences were analysed to identify the priority topics of interest to the participants and the themes within each topic that illuminated experience from different perspectives.

Participants

This report shares the insights of a small group of people who have had personal experience with the mental health and suicide prevention systems between 2012 and 2022. They include:

- people with personal experience of mental illness
- people who have used public and private mental health services
- family members and supporters
- consumer and carer peer workers and leaders
- health professionals working in the frontline of service delivery.

Many had experience in multiple roles and had seen the mental health system from various sides. They came from different geographic areas and experienced the mental health system through the lens of diverse communities, including rural and remote communities, Aboriginal and Torres Strait Islander communities, and various cultural and identity communities.

We would like to thank the following people for sharing their time and wisdom:

- Mr Peter Benn
- Ms Rita Brown
- Ms Melanie Clark
- Mr Neil Collie
- Mr Cameron Grant
- Mr Tim Heffernan
- Mr Graeme Holdsworth
- Mr Douglas Holmes
- Mr Ben Hughes
- Ms Mahlie Jewell
- Ms Katie Larsen
- Ms Ingrid Ozols
- Mr David Pointon
- Mr James Scott.

We would also like to thank the 7 people who contributed to this project and have chosen not to be named.

Acknowledgement of Country

The Commission acknowledges the traditional custodians of the lands throughout Australia.

We pay our respects to their clans, and to the elders, past present and emerging, and acknowledge their continuing connection to land, sea and community.

Acknowledgement of Lived Experience

We acknowledge the individual and collective contributions of those with a lived and living experience of mental ill-health and suicide, and those who love, have loved and care for them. Each person's journey is unique and a valued contribution to Australia's commitment to mental health suicide prevention systems reform.

Limitations

This report presents a snapshot of the experiences of a small group of people. They are a sample of the diversity in the mental health and suicide prevention sectors. No individual story can represent the whole experience of the mental health system. The method used cannot identify all the priorities for people involved with mental health and suicide prevention.

Language in this report

The Commission acknowledges that language surrounding mental health and suicide can be powerful and, at times, contested. Preferences are often not homogenous across groups of people and there is no single consensus on preferred terminology. It is always the Commission's intent to be respectful and use language preferred by most people to whom it refers.

The language quoted in this report is the language used by the people who contributed, and the language used by the Commission and other authors in earlier reports. To maintain the authenticity of the content, no attempt has been made to standardise the terms used.

Were additional commentary has been provided, the language used to discuss these topics has adhered, to the language conventions outlined in the Life in Mind National Communications Charter. The National Communications Charter represents a unified approach and promotes a common language in mental health, mental ill-health and suicide, with the intention of reducing stigma and promoting help-seeking behaviours. For this reason, and within the context of this report, the Commission aligns its use of mental health terminology with the conventions in the Charter.

About us

The Commission:

- monitors and reports on investment in mental health and suicide prevention initiatives
- provides evidence-based policy advice to government
- disseminates information on ways to continuously improve Australia's mental health and suicide prevention systems.

Our work aims to act as a catalyst for change, informing reform strategies, bringing people together to work on change initiatives, and prompting continuous improvement in mental health services and systems.

We work with stakeholders—particularly people with living experience of mental health, their families and other support people—to ensure mental health reforms are collectively owned and actioned.

We work across all areas that promote mental health and prevent mental illness and suicide—not just government and not just health, but education, housing, employment, human services and social support—so that all Australians achieve the best possible mental health and wellbeing (Figure 1).

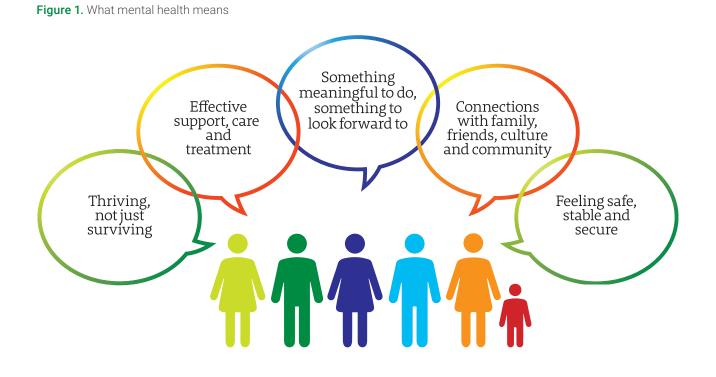
The ultimate indicator of service effectiveness is whether it makes a positive difference to the ability of a person to live a contributing life.⁴

Vision

All people in Australia are enabled to lead contributing lives in socially and economically thriving communities.

Mission

Promote understanding of the outcomes that matter and drive transformational change across service systems for people with lived experience of mental health issues.



Governance

The Commission is an executive agency established on 1 January 2012 under the *Public Service Act 1999* and is a non-corporate Commonwealth entity under the *Public Governance, Performance and Accountability Act 2013.* The Commission is accountable to the Australian Parliament through the Health Portfolio.

An Advisory Board of Commissioners helps set the Commission's strategic directions and priorities. The Commissioners in the 2020–21 financial year were:

- Mrs Lucinda Brogden AM
- Professor Ngiare Brown
- Associate Professor Mathew Coleman
- Ms Heather D'Antoine
- Ms Kerry Hawkins
- Ms Pheobe Ho
- Ms Christine Jones
- Rabbi Mendel Kastel OAM
- Ms Christina McGuffie
- Dr Marshall Watson
- Dr Mark Wenitong
- Mr Alan Woodward
- Associate Professor Elizabeth-Ann Schroeder
- Ms Niharika Hiremath
- Ms Christine Morgan, who is also the Chief Executive Officer.

Our history

The first national mental health plan endorsed in 1993 shifted the focus of the mental health system from psychiatric hospitals towards community-based services. These services were to develop as integral parts of a network of care, with closer connections to consumers and family groups, general practitioners, non-government service organisations, and non-health services, such as housing, disability services, social security and employment.⁵

Twelve years later, gaps in services and poor service user experiences were still common. While reports indicated that progress was being made to reform the mental health system, people in the frontline of mental health care—the people who relied on services, their families and supporters and health service providers—had not experienced the intended change.⁶

This is the context in which the Commission was established in 2012. The Commission's first role was to conduct a comprehensive review of the effectiveness of the current mental health system. Behind the creation of the Commission and the National Mental Health Plans sits a history of more than 50 years of advocacy for change from the mental health consumer and carer movement in the way we care for people with mental illness.

By 2014, the Commission had conducted a national review of mental health programs and services which was published as <u>Contributing lives, thriving communities:</u> <u>Report of the national review of mental health programmes</u> <u>and services</u>. Recommendations from this report were incorporated into the <u>Fifth National Mental Health and</u> <u>Suicide Prevention Plan</u>. The <u>Contributing Life Framework</u> continues to guide review of progress in mental health reform.

Our National Report series

Since 2012, the Commission has published an annual report to the Australian Government and the community on the mental health and suicide prevention systems in Australia.

Summary of findings different stories, shared insights

After a period of substantial mental health reform activity and to mark 10 years of work for the Commission, the Reflections on a Journey of Change project invited a small group of people to share their experience of changes in the mental health system.

In the project, each participant shared their personal reflections. These came from across the mental health sector—from those with lived and living experience, to clinicians, carers and peer and allied workers.

Although no 2 participants had the same experience, their insights overlapped to provide a shared picture of how the mental health and suicide prevention systems are experienced today, and what we can learn from that to inform future plans.

This section presents a summary of key themes across the conversations.

A reflection on 10 years of change

For the participants in this project, change over the past 10 years has been experienced as a roller-coaster of hope, opportunity, hard work, achievement and disappointment. Important gains were seen in some areas, but some key areas were still lagging or going backwards (Figure 2). Despite this, people felt they were part of making change happen. The overall mood was one of hope.

Figure 2. Areas that are improving or lagging in mental health reform

Improving

- Lived experience participation
- Peer workforce
- Community awareness
- Local community initiatives
- Person-centred and family-inclusive approaches

Lagging

- Timely access
- Appropriateness of services
- Responses to suicide risk
- Staffing levels to meet demand
- Secure funding to sustain services

The conversation is changing

(Chapter 1: Attitudes and conversations about mental health)

People had experienced real change in levels of community awareness of mental health and in the openness to talk about mental health and the stresses of life. However, those conversations were usually about general mental health and not about complex mental illness. They linked the growing community conversation about mental health with increased demand for mental health services that has not been matched by increased availability of services.

Also, mental health professionals with lived experience still experience stigma. Changing attitudes in the mental health sector is essential to continue the positive changes observed in the general community conversation.

Lived experience participation and leadership is growing

(Chapter 2: Lived experience leadership)

The voice of lived experience is increasingly heard in mental health. Opportunities for participation for consumers and carers have noticeably improved, including increased opportunities for leadership.

However, there is a tendency for co-production to stop at the design stage—effective co-production in service delivery requires lived experience workers in positions of influence throughout an organisation.

The value of peer work is increasingly recognised

(Chapter 3: Peer work)

The peer workforce has grown and evolved into new roles and become better recognised over the past 10 years. There is a continuing need to intentionally develop and support this workforce.

Concerns were raised about the lack of consistency with which participation has been embedded in routine practice and the extent to which co-production is reaching into service delivery.

People also spoke about current tensions between the clinical and lived experience approaches. Sharp differences in expectations between these 2 professional groups can reduce the opportunities for meaningful co-delivery of services.

Getting the right help at the right time remains a challenge

(Chapter 4: Service accessibility)

Getting access to care is getting harder, with longer waiting times and more fragmented services. People with more severe and complex needs are the ones who have most difficulty accessing services when they are needed.

The expectations of service designers and policymakers do not match the reality of scarce resources and local community issues, particularly in regional and rural areas. Improvements in telehealth and online services has helped some people but not everyone.

Services developed and integrated at the local level were experienced as being best able to meet needs in the context of local community issues and resources.

Responses to suicide and acute illness need significant improvement

(Chapter 5: Suicide and responding to risk)

The conversations about suicide were the most difficult and deeply felt. This was identified as an area where there is a great deal to be done and no immediate experience of positive change.

There is an urgent need to improve the ability and capacity of services to identify, assess and respond to people in psychological distress and to develop safe spaces for them to regain stability. There is a need to integrate the immediate response with follow-up care and support for the longer term to avoid the risk of suicide.

Without acute crisis intervention services, the police, paramedics and emergency department workers are at the forefront of the mental health and suicide prevention system. They need to be supported through better training opportunities, inclusion of a peer workforce and support to ensure their own mental wellbeing.

The mental health workforce is under strain

(Chapter 6: The mental health workforce)

Frontline mental health professionals are recognised as working hard to deliver more person-centred care in difficult circumstances. The mental health workforce is under-resourced, and established protocols and professional boundaries can pressure them to focus on illness rather than on the person.

Better support and more up-to-date education are needed to support and retain frontline professionals. Strategies to ensure that staff are available, and that enough undergraduates are entering the mental health field are essential to support mental health reform initiatives.

A growing understanding of the social determinants of mental health is not matched by action

(Chapter 7: Social determinants of mental health)

People had seen increased awareness of the relationship between social problems and mental health problems, but this has not yet made an obvious difference to the way that mental health services are delivered. Health services lack the resources to address social needs, and take a 'band aid' approach that does not drive sustainable improvements in mental health.

The solution was identified as enabling social services and health services to work more effectively together. This has far-reaching implications for policy, planning and funding but it is essential, as the current lack of integration affects the implementation of reform initiatives.

Connection and community are key to prevention

(Chapter 8: Prevention and community connection)

Building community and developing the life skills needed to navigate the messiness of life are vital for mental health. A key theme in the conversations was connection exploring the ways in which we all need to feel part of a community. The current approach to health services as individual and time-limited were contrasted with the long-lasting value of local relationships and healthy community.

There is still a gap between recommendations and real change to the mental health system

(Chapter 9: The mental health system)

People saw approaches to policy, planning and funding as barriers to change that directly contribute to inequality in access to mental health services.

The way in which funding is structured has an influence at multiple levels—from the need to make a specific diagnosis to access services to the impact of funding models on the viability of local services. Short-term funding and a focus on pilot projects were identified as significant barriers to developing effective local mental health services.

The introduction of Primary Health Networks (PHNs) was welcomed as a positive change, although concerns were raised that lack of consistency and lack of resources limited their effectiveness. The experience of the National Disability Insurance Scheme (NDIS) was less positive—overall, the experience was that the system was not well-designed to meet the needs of people with psychosocial disabilities.

What is still needed

Looking through the lens of this group of people's experiences of the past 10 years, several key areas that still required change and improvement were identified.

These were:

- improved access and development of services when and where they are needed
- better tailoring and diversity of services to ensure they are appropriate for the person
- increased integration of mental health and social support services
- better options for responses to acute illness and suicide risk
- an increased lived experience co-production of services and integration of the peer workforce at all levels
- more training and support for mental health workers and other frontline responders
- initiatives to build community connection
- an openness to learning from past experience and building on existing gains
- a commitment to long-term planning and funding
- better recognition and representation for the diversity of people and lived experiences in mental health.

Over the past 10 years, we have improved populationlevel data collection, and have seen several inquiries that have summarised the common experiences of people who use the mental health system. In this process, it is easy to lose sight of the importance of diversity of experience.

During this project, people shared very different experiences and insights—indeed, capturing this difference was one reason for the project.

Representative structures, such as committees and advisory groups, narrow the focus to a small number of people and a fragment of lived experience knowledge. This reduces the richness of insight contributed to mental health reform and fails to empower some of the more vulnerable.

Participation strategies must be flexible and inclusive, and able to recognise the variation in consumers and their needs. We need to get better at harnessing the power of individual experience as a measure of progress in mental health reform. Findings: exploring experiences

Chapter 1

Attitudes and conversations about mental health



Commonly held attitudes and beliefs about mental health and mental illness influence:

- everyday conversations
- the expectations we have of ourselves in our society (self-stigma)
- the way decisions are made about practical experiences such as employment, education and housing rental
- the way that health professionals approach their work.

A 2012 spotlight report to the Commission explored how Australians talk about mental illness and suicide.⁷ It showed that Australians lacked basic knowledge of mental illness, and that this limited community conversations and prevented people from seeking help. The Commission's 2013 report echoed this:

Public awareness of mental health needs to increase. At the moment I feel like it is a taboo subject in the community and it needs to be able to be talked about more.⁴ Another report from SANE Australia found that stigmatising attitudes towards people with mental illness were prevalent.⁸

Reducing stigma and discrimination was a priority in the Fifth Mental Health and Suicide Prevention Plan (the Fifth Plan). Strategies to raise awareness of mental health and reduce stigma have been aimed at:

- health professionals
- people with mental illness and their family or supporters
- the general community.

These programs have targeted mental health and mental illness in general, and not specific diagnoses or complex illness.⁹

Conversations

Conversations mostly focused on the extent of community discussion of mental health, and changes observed in the communication of health professionals.

Over the past 10 years, people had experienced real change in levels of community awareness of mental health and in the openness to talk about mental health and the stresses of life that often underly mental health challenges. Access to information and resources has improved, and people seeking help are more informed about their own needs. A distinction was made between talking about the difficulties and stresses of life, talking about mental health, and talking about mental illness. People noticed that the discussion was more likely to be about general mental health and not about complex mental illness. They saw a risk of oversimplification and a need to increase awareness of the diversity and complexity of mental illness.

People also linked the growing community conversation about mental health with increased demand for mental health services. At present, services are not able to meet this demand (see <u>Chapter 4: Service accessibility</u>). People saw a need to link health promotion programs to the development of mental health services and resources.

Talking about mental health

For me the biggest thing I've seen change positively over the past decade is that we've become so good at talking about mental health and raising awareness about it. When I came to Australia, there was still such a huge culture of, well, psychologists are only for weak people. Whereas, with my friends over the past few years, I think we're all generally pretty good at talking about mental health. A part of that is through the efforts nationally to raise awareness through a whole bunch of initiatives. But what goes hand-in-hand with that is that we've encouraged people to seek help when they are struggling. We've created this idea that we need to seek help. But when people want to seek the help, they can't actually get in.

Perspective: Lived experience representative, researcher and clinical psychology registrar

6 6 I've seen a massive change in health promotion, health education, access to all sorts of primary health education resources for the community. I think there's been a massive growth in that space for the bulk of the population who just need access to information or brief intervention. I think that's been a really significant change from 10 plus years ago to now. That's been a really big win.

We're starting to see a better educated community and the public in terms of understanding the need for mental health services and when they need them. We've noticed that we're getting much more informed consumers and clients. There's much greater awareness of their rights, what services are available or should be available and treatment options.

What's really heartening is seeing anyone who self-refers, anyone who can walk through a door or pick up a phone, that's a win. Through our new and self-initiated referrals, we're starting to see people who contact us when they feel like they're in distress. The trick there is that we aren't necessarily always able to provide sustained support.

Perspective: Allied health and nursing professional; regional health

People have become more honest and open about mental health. The ones who have been hiding, sometimes for many years, are now identifying that they have a problem and that they want to do something about it. They are happy to reach out. They have reached a point where they know that it is OK to not feel great and they want to know where to start their journey to better mental health. There is more discussion about mental health generally—for example, in the media and RU OK day—and this has helped people to become more open about mental health. There is more recognition and acceptance of mental health issues when you talk to your doctor or your employer.

Perspective: Community peer-to-peer support worker

We talk about mental health more now and we are starting to get the language right. The same level of behaviour change, however, isn't as obvious in how people understand and respond to someone vulnerable or in crisis. All the campaigning we have done—has it made a real difference? We still don't deal well with the complexity of mental health and emotional pain.

Perspective: Living experience, carer and suicide prevention consultant

One conversation highlighted the stigma experienced by people who are involved with the forensic mental health system. The complex intersection between the stigma associated with mental illness and the stigma associated with contact with the criminal justice system present a significant barrier for personal recovery. 6 6 I think that the growth of the forensic mental health system probably happened more than 10 years ago. I think the hope there was that it would really reduce the stigma, because you're sort of really taking people outside of mainstream criminal justice system. There's not really been any major advancements since then. People who are unfit to stand trial or might have an insanity defence are just spending a long, long, long time in prison, and there are real delays in getting them to the secure mental health units in each jurisdiction, because they're just full.

I don't think there's been any real or meaningful shift in stigma for people who commit offences when they're mentally ill, and I think there is still a sort of general kind of fear of people and the unknown, and so that stigma still exists. And that is even permeated right through the court system, so anybody who has committed a crime and may have a defence, the courts are very reluctant to release them. There's still some pretty unfair stuff that happens there because of that stigma.

Perspective: Allied health professional; forensic and justice systems

The attitudes of health professionals to mental health

Person-centred and recovery-oriented care is central to the mental health reform agenda. Achieving this approach requires service providers to work in partnership with consumers and their families, changing the understanding of professional roles and the way that service providers and consumers and carers talk to each other.

People have experienced more helpful conversations about mental health in primary care, and found that mental health professionals are more focused on the person and more inclusive of family or other supporters. Health professionals are better informed about specific experiences, such as sexual abuse and the impact of trauma on mental health.

Participants who are health professionals also noted that the way health services are organised and the content of professional training can pressure them to focus on illness rather than on the person. This created difficulties when they are motivated to partner with the person and their family or supporters. A need was identified to find new ways for health professionals to learn to work collaboratively and flexibly.

Accessing services has been a struggle for our family for lots of years. I won't sugar-coat that. But I have seen change. Our family has seen change. I've seen great difference in my own local health district. The past few years I have noticed there's been an intentional shift around the way that services communicate. There is a genuine knowledge now about the importance of involving families in service delivery.

Perspective: Carer with lived experience of family trauma

6 6 The other thing that I think we've done a lot better in the past decade is that GPs are now a lot more aware about mental health. Ten years ago, I think that wasn't necessarily always the case. We're seeing GPs now asking about how people are feeling and being aware that there are social situations that cause mental health stresses and it's less of a taboo subject. It's less about "I'm just here to talk about your blood pressure and your medications", but thinking more about the person holistically.

Perspective: Allied health and nursing professional; regional health

Another big thing that we've seen, is lots more attention and knowledge about child sexual abuse, and sexual abuse with adults, and the relationship to the very poor outcomes people can experience in relation to their mental health, but also other areas as well, including education, drug and alcohol problems or socioeconomic status. The Royal Commission really highlighted that, and I think one of the positive things with that is now there is a much more sophisticated and sensible understanding of complex post-traumatic stress disorder or borderline personality disorder. That kind of awareness and the actual prevalence rates has been really positive.

Perspective: Allied health professional; forensic and justice systems

6 The people I have learned the most from are the people I have treated. It is so easy to pay lip service to person-centred care while still focusing on the illness rather than the person and their life priorities. We are sitting in an uncomfortable space where you must justify your choices, possibly to the coroner. It sometimes feels so much easier to make the safe textbook decision. However, I take the most joy at working out the sweet spot of the right balance between managing risk and still responding helpfully for the person.

What I see in mental health care certainly isn't by any means perfect at the moment. I know that the COVID-19 pandemic has played a big role, challenging the health system. The way we learn to be doctors makes a difference, and that goes back further than a few years of COVID. We are taught how to be right, and also to be the person who knows best, and if we are not careful, we take these lessons to heart. Less focus is given to the subtleties of finding the right voice, the right words, the right points of connection that make it possible to really engage with another person whose life is in chaos.

Perspective: Psychiatrist; public health

The experience of stigma in the mental health professions

An emerging theme in the conversation was the persistent stigma experienced by professionals working in the mental health field who have their own experience of mental illness or trauma. Some positive changes were identified, particularly in recognition of vicarious trauma and burnout, yet participants felt that there is still a long way to go to reduce stigma in this area.

Stigma around mental illness for health professionals affects their health and their attitudes towards others. There is a relationship between stigma in the health professions and broader community attitudes towards mental health. Changing the conversation about mental health in the mental health sector is essential to continue the positive changes observed in the general community conversation.

6 I think we've come a long way in terms of reducing stigma with mental health, yet there is still a lot of taboo of mental health among mental health clinicians themselves. That's a huge paradox of our profession, because we often preach to reduce stigma in the community, but I don't think we always do that within our own profession. If we start to think about broad system change, then we actually need to start looking within ourselves as mental health clinicians. We have to lead by example before we can see those changes to stigma in the community.

Perspective: Lived experience representative, researcher and clinical psychology registrar

A notable change that has occurred over the past 7 years is a shift in attitudes and de-stigmatisation towards acknowledgement of one's lived experience in academic and training spaces. When I first started my psychology degree and was indicating my interest in the clinical program, I was actively discouraged from speaking about my own personal experiences, as it would likely hinder my progression. Now, however, I think my lived experience was a key reason why I was accepted into the clinical training program.

My lived experience was responsible for my passion for mental health, employment as a peer worker and subsequent experiences working in acute mental health settings. I feel that my peer work experience was really valued by the interview panel for the clinical training program. It's a massive shift and should be the norm.

The other theme I've noticed is the awareness around vicarious trauma, and the fact that there is a personal toll that often comes with this kind of work, which perhaps wasn't previously talked about. It used to be kind of maybe seen as a weakness, whereas now people are much more encouraged to be aware of burnout and how to manage these things—flexible working arrangements, that kind of stuff.

Perspective: Lived experience, military veteran, peer worker and provisional psychologist

Findings: exploring experiences

Chapter 2

Lived experience leadership



The Commission started at a time when the importance of lived experience was being recognised in policy and governance of mental health services through standards such as the <u>National Standards for Mental Health</u> <u>Services</u> (2010) and <u>A National Framework for Recovery-Oriented Mental Health Services</u> (2013).

At that time, there was evidence that the roles for people with lived experience were increasing in number and in level of influence over policy and service planning.¹⁰

Supporting consumers and carers to effectively engage and participate has been a key focus of the Commission's work, promoting consumer and carer participation as a routine practice in all areas of mental health. Recent reports by the Productivity Commission and the Royal Commission into Victoria's Mental Health System have highlighted the significance of lived experience understanding in helping shape the future of Australia's mental health system. I was diagnosed in 1992, and I started my own personal journey with mental illness. I have been involved in the mental health sector since 1993; I was involved in the early days of the National Mental Health Commission. I had the opportunity of contributing to the first reports and the Contributing Life Framework, which takes a whole-of-person, whole-of-system, and whole-oflife approach to mental health. The fact that the Australian Government came on board and adopted this was really important. It recognised what consumers had been advocating for since at least 1996. It meant that people with lived experiences were being listened to, and the bureaucracy was listening to what we'd been saying.

Perspective: Consumer representative and peer worker

Conversations

Conversations focused on the:

- growth in opportunities for people with lived experience to participate
- importance of accountability for lived experience representatives
- need for investment to support development for lived experience leaders.

Overall, the mood of the conversations was positive. The past 10 years have seen growing recognition of the importance of lived experience participation in the conversation, and an increase in their inclusion. This has been limited to some extent by a focus on the design stage rather than full co-production. Concerns were raised about the lack of consistency in commitment to lived experience participation and the lack of support for developing lived experience leaders. Changes must be sustained and embedded across the mental health system. To achieve this, there is a need to support lived experience leadership who are accountable to the people they represent. Participants with connections with the Commission commented on the important role the Commission has played in modelling the inclusion of lived experience in leadership and in providing support through initiatives such as the Australian Mental Health Leaders Fellowship.

An emerging theme was a concern about achieving balanced representation of the diversity of lived experience. There is also a need to support participation for those whose voices are less frequently heard, who represent the diversity of experiences in mental health and suicide prevention. Being inclusive of the richness of diverse experience is a challenge for a system that takes a hierarchical and 'majority' approach in policy and planning, and in collecting evidence.

Participation, leadership and co-production

6 It's been a big 10 years. In the past, not a lot of people in leadership positions disclosed that they had a lived experience. Now there are CEO roles, there are designated roles announced for government, board positions, senior managers, executive roles, the lived experience branch in the state department of health ... we've seen it go from having a consumer and carer representative on groups and being that external engagement, to now actually having authority and roles within organisations.

I really feel that we've just exponentially exploded with where our voice can go now. It's not to say it's everywhere where it needs to be yet, but I do feel that there has been a real shift in the sector's view of what we can bring to the table.

Perspective: Consumer and peer worker; regional PHN

6 6 I have seen a huge increase in the willingness to learn from lived experience. The role is being acknowledged and listened to. However, this seems to be happening in the design stages more than in co-producing services. I don't think it is being implemented on the ground as an integral part of health services.

Perspective: Carer peer worker and advocate

6 6 A lot of people who are designing the system have never used it. It is so important that voice is right at the very commencement of a program. I'm a true believer in co-production, and not this whole 'bring consumers and carers in for a design' and that's the end of it. I certainly felt within the PHN that I was there from the minute the money arrived, to the evaluation roll-up of a program. And I believe the organisation started to realise that having that voice from start to end was really important as well.

Perspective: Consumer and peer worker; regional PHN

We need genuine equal powered co-design. We're here having a shared experience. It's a learning experience and it would be a whole lot better if we didn't think we were more powerful than the next [person]. You know there are lots of loud voices out there. Let's hope the loud becomes loud in a positive way.

Perspective: Carer with lived experience of family trauma

6 Just the mere opportunity to actually have a voice is huge. The consumer and carer movement and how that is impacting on capacity for those to share their lived experiences is really significant. It's raising opportunity for there be a collective voice of "how do we do this better?"

Perspective: Carer with lived experience of family trauma

Supporting lived experience leadership

6 6 There really hasn't been any research into leadership in the mental health sector. We base expectations on business models, and commercial business is not a good fit with social leadership. How do we increase inclusion of lived experience approaches to leadership? We need to do more to develop lived experience leadership. I participated in the National Mental Health Commission's mental health leadership scholarship program in 2018. This was an incredible opportunity to learn and network. It gave me a sense of purpose that I didn't have before. It is a way of building a network of leaders across the sector.

Perspective: Consumer and lived experience worker

6 6 There has been a lot of investment in inquiries and commissions, a lot of investment in institutions, but no investment in leadership for consumers. Leaders can become isolated, not connected to the diversity of people they represent.

Perspective: Lived experience representative and peer worker; PHN

One of the strengths of the National Mental Health Commission is the way that it has embedded lived experience in all its committees and advisory groups with appropriate levels of support for participants. There is a willingness now to try to bring about change. The national and state Mental Health Commissions have helped make this happen. Back in 1994, no-one knew where to start. Now, we have a better understanding. Things are starting to change slowly. There have been big changes in the way that peer workers are engaged and in the level of service user participation.

Perspective: Consumer representative and peer worker

Balanced representation

An issue that emerged across several conversations was recognition and representation for the diversity of people and lived experiences in mental health.

Representative structures, such as committees and advisory groups, can inadvertently narrow the focus to a small number of people and are only a fragment of lived experience knowledge. This reduces the richness of insight contributed to mental health reform, and fails to empower some of the more vulnerable.

At the same time, it increases the responsibility and challenges faced by those who do have a voice into the mental health system. This was acknowledged in the Commission's National Report in 2017.

Maybe the title 'lived experience' is misleading. Lived experience is not one homogenous group. We all have different experiences and different insights. You have to represent what you know, your own experience, not what you think is happening for other people. The suicide prevention sector is a bit lopsided when it comes to representation. It is mostly people who have been bereaved by suicide, and not the people who have attempted suicide and survived. Talking to the bereaved doesn't give insight into the minds of the people who attempt suicide. They can't speak for us. We need much broader representation of experience to ensure we learn from people who have lived through suicidal thoughts and survived suicide attempts.

Perspective: Suicide attempt survivor and lived experience advocate

We do need to be much clearer about what we mean by a lived experience representative. This is an issue now because there is no accountability for representation. People on committees share their perspective without being connected and accountable to the people they are representing. People who get to be representatives sometimes stray into areas outside their own experience. So, for example, carers start to represent consumers.

Both experiences are important and should be represented, but they are not the same and should not be used interchangeably. We need better support for lived experience workers and representatives. Things have improved, but we still need more support and more accountability.

Perspective: Consumer representative and peer worker

6 More work is needed to support vulnerable people to participate. The strongest voices in lived experience representation come from people who have moved through vulnerability. We can become too reliant on those who have found their voice. We need to hear all the different voices and experiences. I love celebrating the diversity and creativity of people with mental health issues, seeing different ways of connecting with the world and with each other.

There are so many strong people who don't fit the norms of society. It is this diversity that helps us to articulate important things about being human—vulnerability, creativity and connection. How do you make sure there is diversity in the lived experience voices that get heard? When we share from individual experience we are seen as a 'rabble'. I have heard that said by someone in government. We are just seen as a disconnected rabble rather than serious representatives of a sector. There is often an assumption that consumer and carer representative groups should join up. The problem is that diverse perspectives get lost.

Perspective: Lived experience representative and peer worker; PHN

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Just as a one-size-fits-all approach to service delivery is not desirable, a uniform approach to consumer and carer participation will not pick up the different types of needs and the most appropriate way of targeting services. Consumer and carer participation strategies should recognise the variation in consumers and their needs and target input accordingly.

Jackie Crowe, Commissioner¹¹

Findings: exploring experiences

Chapter 3

Peer work



3. Peer work

The Commission has consistently highlighted the importance of developing the lived experience (peer) workforce. It identified the need for a National Mental Health Peer Workforce Development Framework in 2013.⁴ The National Lived Experience (Peer) Workforce Development Guidelines were launched in 2021, identifying a thriving workforce as 'a vital component of quality, recovery-focused mental health services'.¹²

6 6 There is a lot of strength in the peer workforce. This work gives you a different way of framing what has happened to you and helps you to construct a positive identity that contributes to ongoing wellbeing.

Perspective: Lived experience representative and peer worker; PHN



Conversations

Conversations noted the evolution of the lived experience/peer workforce over the past 10 years. There is better understanding of this professional role, and more diverse employment opportunities are emerging. People had experienced real growth in this workforce.

However, they also noted that this is not consistent across all organisations. In some places, the opportunities for peer workers are still limited. Some organisations are not yet ready to embed this workforce. There continues to be a lack of appropriate supervision and support structures for the peer workforce. Conversations commented on the need to support organisational readiness to engage peer workers and on the need to implement plans for consistent workforce development. Comments echoed the National Lived Experience (Peer) Workforce Development Guidelines and other reports on this workforce, in stating that clarifying the purpose and scope of lived experience roles is still needed. Achieving this is part of ensuring that lived experience/ peer workers can influence what happens in services and organisations (see <u>Chapter 2: Lived experience</u> leadership).

Changes to the peer workforce

The lived experience workforce has really evolved over the 10 years.

Perspective: Consumer and peer worker; regional PHN

We're seeing the rise of more of these roles coming up, which is fantastic. I have had a range of different roles in peer work over the years, and I think that some of them maybe were a bit more tick the box—a bit more tokenistic. Nowadays, there is increasing recognition that peer support workers bring such incredible value and wealth of experience to the team.

Perspective: Lived experience representative researcher and clinical psychology registrar

6 I started working in mental health in 2015, but I was involved with the sector earlier with my own mental health issues. Things are changing. I don't think there would have been a role like mine 10 years ago. My role has changed a lot over the past 7 years, as it has become better understood and integrated into the way the organisation works.

Perspective: Consumer and lived experience worker

6 6 I've seen the integration of peer work across different services. What I really like about peer work is that it affords people with lived experience the opportunities to shift the public narrative as well as the lens through which we view our own negative mental health experiences. We kind of become better and stronger because of them.

Over time I'm seeing these roles be taken more seriously, and new opportunities and positions are becoming available. I've particularly liked the role of the peer workforce in the community stepped model of care. For example, the Lived Experience Support Service has done some fantastic work providing sub-acute and acute, brief, short-term care to the community, with an ability to escalate or hand over when required.

Further, I believe the use of peer workers at emergency walk-in services have also been extremely useful. A skilled peer worker can quickly build rapport, take a brief history, validate concerns, relieve distress, and orient the client to what they can expect when they see the clinician. I believe these lead to better outcomes compared with services staffed only by clinicians.

Perspective: Lived experience, military veteran, peer worker and provisional psychologist

C There have been a lot of people who have worked very hard creating, for example, the national peer workforce guidelines. The states have done a lot of work, and those frameworks have really helped push and promote lived experience. Now non-lived experience people are our allies, and really pushing to expand this workforce. It's not just us driving that any more. I think that's brilliant, that people see the benefit of having us on the team.

The Royal Commission in Victoria really brought to the forefront that we must do things differently now. And part of that is by expanding the lived experience workforce and hearing more from lived experience consumers and carers on how we need to change. It's exciting to be in that space where you can put forward these ideas and people are willing to listen.

Perspective: Consumer and peer worker; regional PHN

Expanding the peer workforce

6 6 Peer work is now seen really as a discipline—the Cert IV in intentional peer support program has really provided structure around that role, and I think that's really helped embed in services. People understand what a peer worker role is.

There are certainly organisations that are further along and have an understanding that you can't just bring lived experience workforce in without being ready—organisations that have started to look at their readiness, the culture, what exactly they want out of the lived experience roles. There are times where I shake my head and go, "okay, yep, they're not quite there yet". But then other times I talk to people, and I think, "wow, that org has really adapted and really has embedded lived experience in everything that they do". Flourish Australia, for example, promoted early on an approach that looked at every role and asked, "could it be a lived experience role?" I saw that quite a number of years ago, and now I see other organisations starting to do something similar.

Perspective: Consumer and peer worker; regional PHN

6 6 The lived experience workforce guidelines have been very helpful. They gave us more confidence as we developed our own workforce strategy. This has been a key tool for us.

Perspective: Consumer and lived experience worker

6 6 A lot of groundwork has been put in place over the past 10 years, and the Commission has made an important contribution, especially through lived experience participation and the peer workforce guidelines. The way that the language around consumer and carer knowledge and participation has changed over the past 10 years has been fantastic. But it hasn't translated into real change in the way the mental health system works. I think that comes down to investment. For example, there are guidelines, but there is no funding to help implement these. Progress is very piecemeal. There doesn't seem to be a strategy for workforce development.

Perspective: Lived experience representative and peer worker; PHN

6 6 We don't yet have the supervision and support structures we need for peer workers. There are too many people leaving this workforce prematurely because they aren't supported.

Perspective: Lived experience representative and peer worker; PHN

6 6 More needs to be done to support the expansion of the lived experience workforce. The key issues are around where the money is going to come from and who we are going to take it from.

Perspective: Consumer representative and peer worker

Clarity and scope of peer work roles

6 I would like to see a future where peer workers—like other professions—are registered or accredited by some kind of governing body. Without stifling the broad utility of peer work across many domains, I believe there should be clear rules and expectations of the scope of practice, required supervision and ongoing training. This could address many of the limitations and inconsistencies in how peer work is currently implemented, ensuring we are optimally and meaningfully used (rather than in a tokenistic way) in a way that best serves the community. That, alongside professional salary scales and pathways for promotion, would go a long way towards legitimising the profession.

Perspective: Lived experience, military veteran, peer worker and provisional psychologist

6 6 There has been a dramatic growth in peer work since I first needed support as a carer. I am now a carer peer worker, so I obviously support this approach, but I also have a few concerns. There isn't enough clarity around the roles or enough professional support to help people do these roles well. Peer roles are all so different and somehow heading in different directions.

I have a concern about the Victorian Royal Commission recommendations about increasing the peer workforce. You can't just grab people off the street. They need to have training and insight, and they need to be at a time in their own life when they can give back within a professional role, as an employee, and be able to work through situations where they may become retraumatised. There is also greater awareness of a person's support network. Confidentiality is still brought up as a barrier, but services are getting much better at including supporters and at being more aware of the supporter or family's needs.

Perspective: Carer peer worker and advocate

6 6 I feel that some workplaces and programs that employ peer workers aren't always structurally or culturally ready to support or use peer workers in a meaningful way. This can lead to a high degree of turnover in lived experience roles. I've seen peer workers who experience difficulties with mental health issues not supported or given enough time to return to work. I've also seen peer workers who, despite all the workplace support, are not far enough along in their recovery journey to be supporting clients. However, I've also seen that peer workers may leave roles because they are being underutilised and limited in their capacity, because their colleagues worry about their skills or that they are vulnerable or delicate.

Perspective: Lived experience, military veteran, peer worker and provisional psychologist

As peer support workers, we sometimes feel that we don't have a lot of sway. I can advocate for things, but, although my opinions are listened to, that doesn't always translate to change. As a peer worker and consumer advocate it was really hard to enact change. Real influence comes from a clinician and that brings me back to thinking about systems and hierarchies that exist within systems, and it's really tricky to navigate those hierarchies.

Perspective: Lived experience representative, researcher and clinical psychology registrar

We tried to mobilise our peer workforce to support people in bushfire areas, and we were told that support needed to be clinical. In our area, we did still get a lot of peer workers into these roles. As we move forward with disaster planning, how do we mobilise our peer workforce to support people through what is happening?

Perspective: Lived experience representative and peer worker; PHN

Several participants had dual roles as health professionals and lived experience advocates or peer workers. Combining these different perspectives was challenging. People spoke about inconsistency between the clinical and lived experience approaches. Sharp differences in expectations between these 2 professional groups can reduce the opportunities for meaningful co-delivery of services. The different roles led to a loss of some of the most important factors in lived experience work: the ability to model recovery, inspire hope and share insights into how practices affect people's lives.

This is an area for ongoing exploration in collaboration between the consumer and carer sector and the various peak professional bodies. It is vital that we find common ground between professional clinical approaches and lived experience approaches as a foundation for co-production.

6 6 I feel like I'm in this liminal space where I have a lot of peer worker roots and origins, and I see the usefulness and need for peer work, but at the same time I am training to be a clinician. It feels like 2 opposites they're not quite philosophically congruent. On the one side, using your lived experience versus the other, not being able to talk about yourself or any of your own experiences. Navigating these polar opposites is interesting. In the current environment, I don't see there being much opportunity for me to use my lived experience in a clinical setting as a psychologist, which is a shame. We're just so heavily governed, and everything is so strict about what you can and can't do.

Perspective: Lived experience, military veteran, peer worker and provisional psychologist

As a consumer moving through different types of care, you know what is important to you and you can advocate for these things. Now that I'm a clinician, it isn't so easy to advocate, because of systemic constraints and different perspectives on psychology. There is almost a misalignment in terms of goals or what the priorities are for that system. I feel like all the things I worked so hard on as a consumer, I can't actually put them into practice.

I'm finding it frustrating because, you know, they are all the things that I really value and things that I really want to see implemented. I do lots of lived experience speaking. There's always a chance that one of my clients has seen me speak somewhere and obviously knows that I've got a lived experience, and so I've had a lot of conversations with my supervisors about how I would navigate that. There's rules and policies and protocols on how I might navigate wearing both hats, but everyone has been quite supportive along the way. It is a space that hasn't been navigated as much before. There are no guidelines about what the best way forward is.

Perspective: Lived experience representative, researcher and clinical psychology registrar

Findings: exploring experiences

Chapter 4

Service accessibility



Identifying strategies to improve timely access to the right mental health services—the right help at the right time—has been a priority for the Commission from the beginning (Recommendation 2 of the 2012 National Report).²

The right kind of help at the right time means:

- ensuring prompt access whenever it is needed
- coordinated care that addresses the complexity of illness and the broader life issues that contribute to mental illness
- care delivered over years rather than weeks.

In 2020, the Commission reported that people were continuing to experience difficulties getting access to services and navigating the mental health and suicide prevention system.¹³



Conversations

Conversations explored the challenges of long waiting times and navigating a complex mental health system. One participant commented on the difference between the expectations of service designers and policymakers and the reality of trying to access basic services in regional and rural areas. Others commented on the inefficiencies of a fragmented service system with multiple service providers and limited support to coordinate activity or help service users navigate the system. Getting people to the right level of care quickly is essential for good outcomes.

Concerns were raised for people who developed mental health issues during the COVID-19 pandemic, and could not access timely treatment. This is a potential challenge for the mental health system for many years to come. Mental health services are most needed during periods of social and environmental challenge—such as the pandemic, bushfires, floods and economic challenges that lead to loss of income or secure housing. The system is most needed when it and the professionals who work in it are also under most pressure. Strategies are needed to enable greater flexibility in responding to changes in the level of need for services.

Digital mental health services were identified as an area of real change that has been of benefit to some, but not to everyone. Digital health services were seen as providing a much-needed option. But—like many aspects of mental health service—there can be no one-size-fits-all approach to digital services. They provide one option within a suite of services, and there must be clear points of connection between digital services and face-to-face services, including formal health services, social services and local community support groups. The importance of personal connections for building relationships and community was emphasised as being critical to mental health (see <u>Chapter 8: Prevention and</u> community connection).

Waiting times

People had different experiences of accessing services, ranging from being able to access services within a week to having to wait for months for a first appointment. The most common experience was that getting access to care is getting harder. The pandemic had an impact on access, but this was experienced as part of a pattern of increasing difficulty in accessing care rather than an anomaly. People with the more severe and complex needs were also the ones most likely to have difficulty accessing the services they needed.

6 6 I've been quite fortunate because whenever I have needed mental health support from the DVA [Department of Veterans' Affairs] I have been able to get it without significant delay. Its great knowing that there is a hotline that I can call to speak to a qualified mental health nurse—and get me into whatever service I need within a week. Since the service reshuffle that happened a few years ago, I've never had to wait more than 5 minutes to speak to someone. But at the same time, my mental health issues are largely resolved, and I think where the persistent gap is when someone is having a more acute mental health crisis, and they need to see a psychiatrist. That's where the bottleneck is with significant delays. If you need to see a psychiatrist, then you probably need to see them urgently.

Perspective: Lived experience, military veteran, peer worker and provisional psychologist

6 I think over 10 years, there has been poorer outcomes for people with very serious mental illness. People don't get into hospital when they need to be in hospital as fast as they need to be, they don't get to see their mental health provider in the local state service, or if they're seeking private psychology or whatever there are always waitlists. I see real delays in accessing treatments. I don't think it's really measured well, but I think that there are instances where people end up in custody rather than in treatment settings.

We also see people skipping medication because of the cost or an inability to get to the GP to get those script renewals and those kinds of things. I see a wide range of people in my job who are suited to the private system, but the challenge is just finding somebody, not having to wait 5 or 6 months to get in, and then being able to afford the frequency that's required to do those kind of sophisticated therapies.

Perspective: Allied health professional; forensic and justice systems

With everything that was going on, we weren't really surprised that depression returned after several years of living well without medication. They tried to get a psychiatrist's appointment in public health. The next appointment was 9 months away. Private health insurance didn't help either. There are so many forms to fill in for admission. When you are in crisis, you just can't read. Thinking about completing them is near impossible.

It has been about 8 years since the last time we needed this level of mental health care. The problems we experienced then are very similar to the problems we experience now, except that getting access to care has become harder. The public message seems to be 'just ring for help and you can get what you need'. Our experience is that the help isn't there. A telephone number is not enough when someone doesn't feel safe.

Perspective: Mother of young adult with mental illness

Our young people, our children in that space [pandemic-related isolation] for over 2 years ... I'm seeing a lot of young people developing severe anxiety and depression from that period of time. Certainly, my daughter is.

But accessing care is really difficult for those people. Support for young people is scarce. I'd hate to see the long-term impacts on that cohort if they can't get the care that they need early on. I am involved with some of these state and national decisions from a regional and rural perspective. They sit there and they talk about access to services through GPs, for example, and you sit there and you go, "what GPs?" If we can get into a GP at all, it may be 3, 4, 5 week wait before we can get an appointment. There's an assumption that we have access to the same care that the metro people do, and the fact is it's not always the case. It is inequitable. And then try to get a bulk-billing GP, or a bulk-billing psychologist. We don't have options. It is really difficult for people on low incomes.

Perspective: Consumer and peer worker; regional PHN

Access to public inpatient care

People said that hospitals are not the best place to support mental health recovery, but are still an important part of the full spectrum of mental health care. Inpatient care ideally provides a safe, controlled environment in which people can stabilise their mental health during an acute episode of illness.

The development of primary and community care has been a focus in mental health reform, yet much of the spending on mental health services has been needed to maintain inpatient services. Despite this, between 1998 and 2017, there was a reduction in the number of psychiatric beds in Australian hospitals.¹⁴

The conversations noted that the pressure on inpatient services reduces access and increases premature discharge. People had experienced a reduction in access to inpatient care over the past 10 years.

6 I think generally, there's been no improvement. There are areas that have changed, but, overall, the pressure on state services is higher than it's ever been, which means accessing treatment is harder. There's been a reduction in acute care, and that has really meant that some people and their families have really suffered while trying to get the intense treatment and support that they need. The level of acuity is really much higher on those acute wards than it's ever been. The pressure is really high. The wait times in emergency departments are much higher.

Perspective: Allied health professional; forensic and justice systems

C Too many hospital beds are taken up by people with nowhere else to go. If we focus on finding stable supported accommodation for vulnerable people, people on NDIS packages or people who need aged care, then within 5 to 10 years, we should be able to free up hospital beds so that we can provide better hospital care as well. We could make the transition out of hospital so much easier for people if we had 7-day follow-up, good links back into the community and a common set of paperwork that a person has access to.

Perspective: Consumer representative and peer worker

6 People are spending shorter periods of time in inpatient treatment. We seem to only see people when they are at the pointy end of mental illness. We move people out when they are okay, but perhaps not ready to thrive. There is always bed pressure. How do I gauge which patient needs admission most? How can I decide who needs it most and who to move on from inpatient care a little earlier? It is a juggling act, and you do the best you can.

The COVID-19 pandemic has made a difference. People have a lot more distress and difficulty coping. We are seeing more substance abuse-induced psychosis, more suicidal presentations and more personality disorders.

There are lots of unhappy people in a psychiatric ward, and it's not just because of their illness. They either don't want to be in hospital, or they do want to stay and know that they will be discharged sooner than they would like. Inpatient care doesn't work well for anyone. I want to avoid admitting people. Hospital is just not the best environment for people's mental health. But if they do come in then I want them to have the very best experience that they can have.

Perspective: Psychiatrist; public health

Alternatives to inpatient care

The increasing difficulty in getting access to psychiatric inpatient services would not be seen as a disadvantage if there were alternatives available. The experience of participants was that better approaches could be delivered in the community. They emphasised the need for safe places, to achieve stability during crises and acute episodes of mental illness. Their definitions of 'safe', however, differ from those used in hospitals. Safety was a feeling created by a gentle physical environment, supportive care from staff who could acknowledge the reality of pain and distress, and an opportunity for respite for a few days.

Where services had been experienced as helpful, they shared some common characteristics:

- They were available when needed with prompt access.
- They were not delivered in hospital inpatient settings.
- They addressed the complexity of illness and of the broader life issues that contribute to illness. Sometimes this was built into the program and sometimes it was provided by servicer providers outside the scope of their work, because they understood the need to address social determinants as well as clinical symptoms.
- They were coordinated (case managed) and long-term, providing support for years rather than weeks.
- They were experienced as personal and supportive.

These programs make a longer-term commitment, and provide more holistic support and care coordination. But they need to be available. When they are not, inability to access inpatient care or to stay in hospital becomes a critical issue. There was a sense that good community initiatives that could provide this type of care had been lost over the years, with changes in funding and priorities. 6 I think the whole mental health system is moving in the right direction in many ways. There is increasing recognition of recovery and wellbeing models and more recognition of trauma-informed practice. We are having more conversations about mental health. There has been a reduction in stigma, and more acceptance of reaching out for help. We are starting to deliver alternatives to more traditional treatments. On the other hand, the mental health system is still really hard to navigate.

Perspective: Consumer and lived experience worker

6 In 1992, I went along to my GP, and he referred me to the mental health team in my area which had started a program called SAFE. Anyone who fronted up for the first time was given additional support, and that meant more time with the case manager. In my case manager, I found someone I could connect with. I was lucky that there were no psychiatric inpatient beds in the area, and so I was kept at home and supported by the team for about 2 months. I was lucky enough to be sent to the Black Dog Institute for a proper assessment. That's one of the things that I think is missing today—it's hard to get access to services. A lot of what I do today is trying to replicate what happened to me in 1992.

Perspective: Consumer representative and peer worker

6 In 2013, I had another long period of challenges which all led to a series of inpatient admissions (most by coercion) in public hospitals. The only positive thing about that time was getting into the Project Air Strategy Lifeworks pilot program. This is an international strategy for people with severe personality disorders who are a 'repeated drain' on public mental health care. It promotes compassionate and evidence-based treatment. This was where I first experienced DBT [dialectical behaviour therapy].

At that time, the project was working with people who were at high risk of dying from suicide. I was with that program for 4 years—longer than I was supposed to be, but continuity of care was important to me, and the clinicians did everything they could to keep me engaged. They pushed the boundaries of their roles and used their skills to help me with things like finding stable housing, leaving violent relationships, and navigating other systems as well as my mental health. I know they weren't paid for a lot of that work, which highlights how the system fails people constantly—people are expected to constantly work outside of their job roles.

The program was really, really hard work but it was worth it, and I got through it because others supported me and went above and beyond. After we addressed some of the basic human rights and needs, life settled. I got back into education and work, and found accommodation. I had stability and a lot of support wrapped around me. I didn't need to go back into the public system for about 8 years. A big part of gaining that stability was intentionally keeping away from public health as I became aware of how much damage had been done to me. I qualified as a therapist. I am now the one delivering DBT. I want to say that the public health system is better now, but it is not. It feels worse, and I wonder if this might be because I am older—the funding is so geared towards young people, and I carry some very big, complex and long-standing psychiatric presentations. My diagnosis of 'complex trauma' threw me back into the 'too hard, can't be helped' basket. For one thing, most hospitals aren't delivering DBT any more, as it is seen as being too expensive and takes too long, yet it is the thing that works, it is the evidence-based treatment for personality disorders. The reality is that holding someone on a ward is not trauma informed. Hospitals are just not the right place to be when you have complex trauma. How much money are we wasting keeping people in the wrong kind of care?

It would be great if we could replace the psychiatrist's daily rounds with psychologists who can provide treatment. I have never received treatment while on a hospital ward. The focus is on getting you out of hospital or keeping you in hospital against your will. It isn't on helping you to recover. My experience with hospitals is like 'Hotel California'—this very exclusive place you can't get into and once you are in, you can never leave.

Matching services to need

6 Our referral system is broken. You should be able to get to the help you need when you need it. It doesn't matter whether you need help from a health service or whether you need a social prescription. We need a single point of entry, somewhere you can connect with a real person, have a safe conversation, and work out together what you need. This is more than a 15-minute consultation. It's longer and more personal. We need link workers who can work with you to identify what you need, who can put together some sort of plan and who can make referrals.

Perspective: Men's preventive mental health and mutual support

6 6 Services might not always be adequately calibrated to match the acuity of service user needs. You might have someone with severe and complex mental health needs coming to a service that specialises in more mild or moderate presentations. That mismatch can lead to a not-so-positive experience for a consumer, which can make them more reluctant to seek help in the future.

Perspective: Lived experience representative, researcher and clinical psychology registrar

6 6 People are now embracing psychological care, and want specialised services. It is less stigmatising to access mental health services but maybe some people are being over-serviced. It is harder to discharge people. Efficiency can go down if people are not getting connected to the right service provider. Someone can be referred to a psychiatrist with a simple phobia. Conversely people with complex mental health problems, such as bipolar disorder, may be seen by an early career psychologist in private practice. Care is not matched to expertise. Some of this may be driven by consumer-based choices, but some of it is down to inefficiencies in the system.

Perspective: Psychiatrist and researcher; public and private health

6 6 We're tending to delegate out responsibilities to more and more different types of providers. Moving away from having a person being able to access a provider that can treat them completely or treat them holistically.

I feel like we're still parcelling stuff out more. That need for specialisation is fracturing the patient journey. There are too many service providers providing bits of service and bits of treatment and bits of support. I can see it getting more diversified and broken apart and therefore more competitive.

While we're looking at increasing consumer choice and access, at the end of the day you want to make sure that the services being provided are safe, effective and sustainable. Potentially, you will have one client have up to 3 or 4 different providers who have all been either subcontracted or co-contracted to provide a particular service. That's certainly not conducive to trying to keep that person well and healthy. The more you split things apart, the more risk you add to the system. There has been a continued push away from case management and care coordination, and we're having to focus a lot more of our energy and resources into acute management of clients.

Perspective: Allied health and nursing professional; regional health

Spotlight Supporting families

Services and policies rely on families and informal supporters. This needs to be acknowledged in service design and development, together with the stresses that come with those supporting roles. Families need help as well. Failure to provide this inclusive support places everyone's mental health at risk.

One conversation explored the needs of families as the person they support transitions into and out of care.

6 I speak through the lens of someone with lived experience of early adverse circumstances, a lived and living experience of trauma and supporting family members with mental illness.

Recovery is just hard, full stop. We're all sort of in it together, and when an individual is stepping through a recovery process, the whole family, all those that support them, go through it as well. There are no hard and fast rules as to how to do that and how to come alongside and support a loved one to do that. There just needs to be capacity built. I'm just hopeful that there can be something else that is established that can continue building capacity that's not currently there.

So often I come across families who are struggling with the fact that they have a loved one in a rehab facility and their loved one is off on their recovery journey, and yet the families may not be as involved. There's no real transition process that empowers family members to navigate forgiveness. Once a loved one steps out of a rehab facility, for instance, or it might just be a hospital stay there's not a lot of time or information or support for those who then need to wrap support around their loved one. Some support for transition services would be amazing. I think cultural diversity is really important, and it's important to nurture the identity of all cultures. There are things that still need to change in this area. Every community group needs to be educated around what mental health is for others and what mental health is for themselves and the role that they play, too, in preventing suicide. We need education for families around responding to risk of violence themselves, building capacity in families within their cultures. Something as simple as knowing the right things to say. What do family members say so their loved one is feeling heard and so that carers can also feel like they're making a difference and not actually increasing risk as well. It's like a shared journey that still needs to happen.

Perspective: Carer with lived experience of family trauma

Telehealth and online services

Digital strategies have been promoted as a way to improve access to mental health information and services, including encouraging prevention and earlier intervention. The Australian Government launched the Australian Digital Health Agency in June 2016, and, in 2017, a new digital mental health gateway went live to help people navigate the system and make informed choices about their care.

The unexpected benefit of the COVID-19 pandemic has been the increase in availability and use of telehealth services, which showed that this is a viable way of getting services to people who are isolated or who have other barriers to using face-to-face services.

However, the Commission has identified concerns about accessibility to the internet and other digital technologies, as well as digital literacy—in particular, for people in regional and remote locations, and older Australians.¹³

The conversations emphasised this tension between the benefits and limitations of digital strategies depending on people's access to reliable technology. **6 6** The one good thing that the pandemic did develop was the online stuff, which has made access to therapy a lot easier for some people. And it just does suit some people better, particularly in the rural and remote areas, where they can now really access good-quality services. Lots of people in [location] have psychiatrists that are on the mainland and they see via video. It's just shown us that you can actually connect and have therapy online. It doesn't suit everybody, but it does suit quite a lot of people.

Perspective: Allied health professional; forensic and justice systems

6 6 I question the value of online services. I understand that it can be helpful for people who are able to navigate the internet, and have stable internet or telephone connections. This was problem in Tassie when crucial phone calls and Zoom meetings with somebody in immediate need were dropping out, but it feels like a poor cousin compared to personal contact.

Some people don't have the capacity to make decisions about what they need just based on a website. Finding information and comparing different services is an extraordinary challenge when you are stressed, distressed and probably exhausted. When your life is in chaos, you just aren't organised enough to assess what's right or make a decision. We need people who are there, available when they are needed to have that conversation.

Perspective: Men's preventive mental health and mutual support

Restrictive practices

It is reasonable for consumers and carers to expect that contact with mental health services will improve their mental health and wellbeing.¹⁵ Yet that is not always the case.

6 6 I first came into the mental health system a long time ago when I was 23. I came out of hospital that first time with a diagnosis and a future that involved further admissions to institutional settings 2 years later. I was confronted by the fact that a system that was supposed to help me was violent and harmful, so I avoided it, with my next hospitalisation 20 years later.

Perspective: Lived experience representative and peer worker; PHN

The Commission's <u>Position Statement on Seclusion and</u> <u>Restraint in Mental Health</u> supports working towards the elimination of seclusion and restraint of people experiencing mental health difficulties in mental health services.

In 2019, the Commission worked with the Australian College of Mental Health Nurses and other key stakeholders to develop a <u>National Framework for</u> <u>Ensuring Safety in Care and Safety for Staff in Australian</u> <u>Mental Health Services</u>. Making safety and quality central to mental health service delivery was a priority in the Fifth Plan.

In the conversations, people had seen a reduction in the use of seclusion and restraint in inpatient settings over the past 10 years, although it is still a problem and there are barriers to further reduce these practices.

6 6 Restrictive care is used less often. I have noticed that it's become more positive in the way that communication is happening. It's certainly a sore point for a lot of families. Nothing prepares you to see your loved one restricted and restrained. I do believe we have a way to go.

Perspective: Carer with lived experience of family trauma

Over the 12 years that I have worked in public health, I haven't really seen any big changes, aside from the Mental Health Act. Practices are quite structured. I could go into any other hospital and find the same things happening. However, we use restrictive practices less often. We are moving away from just reducing harm and towards achieving the person's goals.

Perspective: Psychiatrist; public health

One of the reasons we are still seeing seclusion and restraint being used in hospitals is actually in the buildings. Where wards are in old buildings, they don't have access to the space they need, they don't have other viable options. It takes a lot of resources to do this work properly more staff and more space. As we create new psychiatric units, I think we will be less likely to see seclusion used.

Perspective: Consumer representative and peer worker

We often talk about the terrible things that happen in the forensic system. This is a failure of a system that assumes that it can cure our minds with pills, control and isolation. Just by being with people, peer workers can reduce risk and the need for isolation.

Perspective: Lived experience representative and peer worker; PHN

Findings: exploring experiences

Chapter 5

Suicide and responding to risk



The Commission's second national report included a recommendation on prioritising local service responses for the prevention and reduction of suicides, with specific support for those who attempt suicide.⁴

While recognising that it would take time to implement these changes, the Commission expressed concern that there continued to be inadequate care and support for people in crisis, and insufficient training in suicide prevention for people working in health, allied health and community sectors.¹⁵

In 2019, the Australian Government committed to Towards Zero, starting with the appointment of a National Suicide Prevention Adviser. The Government's response to the Adviser's Final Advice is outlined in the <u>National Mental</u> <u>Health and Suicide Prevention Agreement</u> and informed mental health funding in the 2021–22 Budget.

Conversations

Conversations about suicide and the approaches currently used to reduce risk were wide ranging, and included emergency department and police responses, assessing suicide risk and providing support after a suicide attempt. This was the most difficult and deeply felt part of the conversations. It was identified as an area where there is a great deal to be done and no immediate experience of positive change.

Approaches to the provision of acute crisis intervention services have a mixed history. Current assessment approaches for suicide risk are not appropriate for many people. People are being missed in emergency departments or sent home when there are no services available. At its worst, the system is seen as negligent or traumatising towards people experiencing psychological pain, especially for those who have a history of trauma.

There is an urgent need to improve the ability and capacity of systems and services to respond to mental health crises. There are evidence-based models to learn from, and resources informed by people's lived experience to guide learning and practice.

Without acute crisis intervention services, police, paramedics and emergency department workers are at the forefront of the mental health and suicide prevention system. To enable them to provide effective support, first responders must:

- be provided with education informed by lived experience and evidence
- work with and be supported by experienced mental health staff in every emergency department, including peer workers
- be supported to ensure their own mental wellbeing.

The conversations were very similar to those heard during the recent inquiry into suicide prevention, summed up in the first interim report from the National Suicide Prevention Taskforce:

Suicide prevention efforts must learn from those who experience suicidal distress and suicidal thoughts, and from the resilience displayed by people who are recovering from suicide attempts ... We must also urgently transform our service system, a system that people describe as disconnected, crisis-driven and dehumanising, where the traumatic and systemic factors that often contribute to suicide are rarely acknowledged. **Christine Morgan, National Suicide Prevention Adviser**¹⁶

There was no expectation that people would have experienced real change in responses to suicide risk in the brief time since the Suicide Prevention Adviser presented her final report to the Australian Government. However, the mood of the conversation was one of urgency and frustration. Concerns were raised that the accuracy of the report on suicide prevention would be reflected in real action.

6 The suicide prevention report was fantastic. I still have to ask if we are implementing the recommendations in the right way.

Perspective: Suicide attempt survivor and lived experience advocate

Spotlight

Identifying people at risk

A 2019 Spotlight Report to the Commission identified that the high level of stigma associated with personality disorders contributes to challenges in accessing care.²³

I am no longer an active carer. My daughter died by suicide. She could not find the services she needed to help her tolerate the pain and distress of living with BPD [borderline personality disorder]. She fought hard to live. As contradictory as it may sound, one of her survival strategies was to take overdoses. And, one time, help did not arrive in time.

When she was an infant, we experienced domestic violence. I was told by professionals at the time that this could change the way her brain developed, but no one offered any support. I was in survival mode. My life was focused on getting us somewhere to live, paying the bills, keeping us physically safe. I didn't know what to do to help my daughter process and recover from the trauma. I think about how different life might have been if there had been services for her (or for us) when she was still a young child. That was more than 30 years ago, and I don't think that parents escaping violence can rely on getting help now any more than I could.

Since she died, I have seen the same things happening over and over again for other people with BPD. The distress can be so intense that the person doesn't feel they can survive another moment. The idea that there is a way out of the pain is compelling. If taking an overdose seems like the only option, then that is the path they will follow. They aren't trying to end life, just to end the pain. Accidental death is a reality. The way most services assess suicidality doesn't work for people with BPD. Some people with BPD feel suicidal most, if not all, the time. It's not that they have a plan or a clear intention, they just feel totally overloaded with intense emotion that can be quite destructive. Advice like 'just go home and eat some ice cream and you will feel better' is harmful. It dismisses their very real distress and is perceived as 'no one understands me', and leaves them with no helpful way of managing that distress.

I believe very little has changed in the mental health sector for people with BPD. I still hear of people being denied access to mental health services because of their diagnosis. The person with BPD is frequently seen as the 'problem'. The ongoing intensity of their needs is seen by some organisations as 'clogging up our waiting lists'. For people at the lower levels of complexity, and/or who can afford private care, there may have been some positive change. For those with complex needs and a high risk of suicide, they are just bouncing in and out of emergency departments.

Generic treatment services aren't equipped to meet the specific needs of people with BPD. Unfortunately, it appears that early contact with generic services who know little about supporting a person with BPD may do more harm than good. Meeting the needs of the less severely unwell shouldn't be achieved at the expense of people with more complex needs.

Perspective: Mother of young adult who died by suicide and carer peer worker



Emergency department responses to risk

In the 2018–19 financial year, 3.6% of presentations to emergency departments were related to mental health concerns. These people experienced the longest waiting times, and sometimes left the emergency department before care had been provided or were discharged without a follow-up plan.¹⁴

The Commission noted in 2018 that the continued increase in the use of emergency departments to manage acute episodes of mental illness suggests that people are not getting the care they need in the community.¹⁵

Participants identified that there is a need to develop safe spaces for people in psychological distress. People in crisis need calm spaces, where the intensity of emotion, stress and distress can be contained rather than made worse by noise and unfamiliar routines.

6 6 The environment of an emergency department is unsupportive when your mind is in turmoil and when what you need is a calm and supportive space. There is nothing in this environment that can help a person to reduce the intensity of their emotional distress, nothing to help them regulate their distress. What people need is a safe place that can re-regulate their overwhelming emotions. Maybe a place where they feel it's okay to let go of their battle to stay alive, and it's okay to let someone else be responsible for their wellbeing for a while, a short-term admission to hospital that is providing them with a shortterm space where they can regroup and learn some skills and strategies. Instead, they are left in emergency feeling increasing distress, and then sent home without support.

There seems to be a lack of understanding among health professionals of just how intense and destructive the emotional overload can be. Frequently, people aren't treated as if they are in real pain, or others feel the pain is selfinflicted and they should just try harder and 'snap out of it'.

Rather than clinicians or supporters offering wellintentioned, yet superficial, solutions to make people in pain feel better, they need to have their reality acknowledged. Trying to come up with solutions just adds yet another burden on the person, a sense that, of course, they should be able to fix this for themselves.

Perspective: Carer peer worker and advocate

6 6 In 2020, I went to the ED [emergency department] because I knew I was at risk of suicide. We were in the middle of the first wave of COVID-19 and people were dying and very ill. The system was collapsing and the closest hospital to me was ground zero. My ED doctor was sympathetic, but psychiatric services had frozen and I was sent home and given benzos.

In 2021 things got even worse. I still couldn't get admitted to a psychiatric ward despite a suicide attempt at home, reported by both my psychologist and GP. They were either closed or they had active COVID cases on the ward and couldn't risk admitting me as I am immune compromised. I was even turned away because I had already attempted suicide, and the hospital wasn't equipped to help me.

The literature shows that people with personality disorders who are suicidal can benefit from brief admissions of around 48 hours. Just long enough to help them become calmer and more stable. My experience last year was an 11-hour wait in emergency, and then being sent home without a psychiatric assessment because there was no psychiatrist available.

Police as first responders to risk

When I attempted to end my life 10 years ago, I was found by the police. They were great but there was nowhere to send me, so I spent the night at the police station. There's lots of things in the system that just aren't set up to support someone who is feeling suicidal. There was nowhere that I could safely admit to struggling with suicidal thoughts. If I shared with anyone, I was likely to end up in the back of a paddy wagon. Everyone wanted to intervene and take away my control over my life. If other people think you have a problem, you end up with the police on your doorstep. The fact that the police are the first point of call may reduce immediate risk, but it increases the stress for the person.

Perspective: Suicide attempt survivor and lived experience advocate

6 I work in the SAPOL [South Australian Police] Mental Health Portfolio. I'm a conduit I suppose between police and mental health services. About 60% of the incidents that we attend have a mental health component. I receive the concerns and the issues from what our police are experiencing on the road, and then pass on these concerns to our health people. I like to provide a problem-solving approach to these issues where possible.

We've always responded to disturbances in the community, obviously, but there were previously more suitable referral services; Acute Crisis Intervention Service, or ACIS, was a 24-hour response service for people experiencing mental health crisis, and that particular service ceased operation in 2011. Since that time, this has resulted in police having to deal with many more incidents of people experiencing mental health crisis, especially after hours.

Police having to assist someone in a mental health crisis isn't really a good fit from a treatment and ongoing support perspective. We're happy to go and assist them, no issues with that at all, but it's about what happens after that, which isn't really the police role. In the absence of other options, we take on that role to a degree, and this is a point of frustration for police.

Perspective: Police and mental health

6 6 I hate that we live in a society where police respond to mental health crises. People with guns should never be around people with mental health issues. People need to be comforted, they need human contact, they need to be heard. Sending the police out to people who have been traumatised, people who have experienced violence, people from First Nations communities just doesn't work. When that is your background, the police are not your friends. They are not people you trust. When they smash down your front door and strip search you, they just add to the trauma.

None of the focus was on what would help to stabilise me. When dealing with someone in distress, the person helping needs to be as calm as possible. Not looking for danger. The thing you learn about the health system is: don't come here too often, don't ask for help too often, don't admit to suicidality too often, or they will punish you. They will send the police to your home as they have done with me many times.

Follow-up care

A 2015 Spotlight Report to the Commission made a link between failure to provide outpatient follow-up care and increased risk of re-attempt and death by suicide.¹⁷

Conversations highlighted that there is also a need to integrate the immediate response with follow-up care and monitoring. Crises do not happen in isolation from daily life, and support is needed for the longer term to avoid the risk of suicide (see <u>Chapter 7: Social determinants</u> <u>of health</u>). There is inadequate early intervention, especially for people affected by domestic violence, to reduce the risks associated with trauma.

6 6 There is an assumption that mental health care services will support people after a suicide attempt. Those services aren't available when they are needed. The focus is on risk avoidance more than trying to understand and support the person. I was in and out of private hospitals and health services for about 4 years. Even though it was hard at the time, the private health system was pretty good to me. My GP and private health services helped me to avoid a second attempt at suicide. We must improve our focus on after care. We need to wrap services around people who have attempted to end their life. People who have attempted suicide are not identified in high-risk groups. We are invisible.

Perspective: Suicide attempt survivor and lived experience advocate

We need places where we can safely share what is going on in our minds without the fear that we will be taken to hospital, without the risk that the police will be knocking on the door and taking us away without our consent. This is the reason for some of the peer groups. They give people a chance to be heard without the threat of the health system. We are on our way to understanding that there are different ways of doing things with services like the Safe Havens in New South Wales. We have peer workers in more areas, including outreach teams. We need more options in community with non-health services and local initiatives working alongside the health system.

Perspective: Lived experience representative and peer worker; PHN

6 6 The Acute Care Team did contact me by phone afterwards. The problem was they don't leave a number where you can get back to the person in the Acute Care Team who was calling you. You must go back through the system again from the beginning, telling your story all over again, and then they pass the details on to the right worker who will phone back later. The cycle starts all over again if you miss that phone call. Even my psychologist gets incredibly frustrated by it. Failing to answer the phone is noted on your record as 'refusing to engage'. They seem eager to have you miss these calls and in discharge summaries use the 'refusal to engage' as an excuse to discharge you without letting you know. I've been re-referred after being discharged without contact by my GP and psychologist several times.

Assessing suicide risk

6 6 I am the mother of a young adult who has had mental health challenges since they were in their teens. The past 2 years have been really difficult. They tried to end their life 18 months ago. The emergency department was unable to offer help. The first thing they asked was "have you got a plan?" Without a plan, they seem to believe that there is no imminent danger, so you just have to go away, and call back when you "have made an attempt, feel worse, and have caused serious self-injury".

Waiting times are already stretched. Help is only for people with serious physical injuries or health problems, and they too are being told that our health system can't cope with more people in need of medical assistance. Asking about plans isn't helpful, especially not when the person is impulsive. Emergency were not paying attention to the intensity of the psychological pain.

It's negligence to insist that people physically harm themselves before they can get help. We still don't have the flexibility in our resources to meet the needs of people in crisis, and that puts people's lives at risk.

Perspective: Mother of young adult with mental illness

6 6 The triage processes used in emergency departments don't identify people with emotional distress. People are rarely identified as high priority which is how they end up spending hours waiting in a stressful place that just makes everything seem worse. Staff are starting to understand and recognise people in psychological distress, but it doesn't happen in every area. Whether there are experienced mental health staff available to the emergency department makes a huge difference. The further you go from the CBD [central business district] the worse it gets.

Perspective: Consumer representative and peer worker

A lot of my family's experience has been supporting a loved one who's been suicidal in community, and seeing how the process is not seamless. There's lots of education that still needs to happen there for all services who were involved, and all stakeholders who are involved in responding well to crisis and mental health and suicide prevention. It's certainly an area that I believe needs to improve. But I don't think it will improve until we can have fair education across all stakeholders, including police and paramedics.

Perspective: Carer with lived experience of family trauma

Findings: exploring experiences

Chapter 6

The mental health workforce



The mental health workforce is broad. For example, it includes mental health professionals, lived experience workers, first responders, allied and physical health professionals, social service workers, education providers and staff in the justice system.

A high level of staff turnover is a key issue confronting the mental health workforce. Factors that contribute include stress and burnout, staff shortages resulting in excessive workloads, and insecure tenure, especially when funding is for short-term projects. This has been exacerbated by limited training in key areas such as suicide prevention, the challenges of working in rural and remote locations, and reduced time for training, mentoring and supervision.¹⁵



Conversations

Conversations focused on under-resourcing of services and consequent stress and burnout. The experience was that there is insufficient staffing to meet the need for mental health services, which contributes to stress, burnout and a high staff turnover rate. This, in turn, reduces the number of staff available, and may be a factor in the difficulty of recruiting new workers, especially in regional areas.

Participants experienced the tension between maintaining a person-centred approach and complying with service protocols and funding models. Professional training was not always consistent with the latest evidence-based practices or the collaborative approaches that are needed. Participants said there is a need to keep training up to date with emerging evidence and to embed lived experience knowledge into training. Promising strategies were identified to improve training and support for health professionals. Interesting initiatives were described that use resources in different ways to help frontline workers confidently deliver effective services without increased stress.

While improved training and support are important, there is a more basic need to make sure that enough staff are available, and that enough undergraduates are interested in committing to mental health as a field to work in for the future. This is an essential foundation for all mental health reform initiatives. The National Mental Health Workforce Strategy, currently under development, was seen as a positive step that would contribute to improved services and service outcomes.

Stress, burnout and staff turnover

6 6 I think, generally, people who work in the industry are feeling higher levels of burnout and higher levels of just feeling as though they are trying to keep their head above water, rather than working really positively and proactively towards positive change. There are challenges in recruiting and then retaining staff as well. We have a real problem with recruitment and retention [in all mental health services].

At one stage every single psychiatrist in our hospital was a locum. They fly in and out again. They just don't have that same skin in the game, the treatment decisions are not made with what's going to be happening at discharge, or in 3 months or 12 months, or how do we stop this 2-year cycle of coming back to hospital, or whatever. That's both a recruitment and a retention problem.

Perspective: Allied health professional; forensic and justice systems

6 6 There have been significant changes in mental health in the years I have been working. Unfortunately, we are currently at staffing crisis levels in all our mental health teams. I have never seen it this bad. I am working 7 days a week across both the community and crisis assessment and treatment teams. The burnout, vicarious trauma and everyday stress that is put on clinicians working short staffed is significant. The lack of nurses going into mental health as a specialty is a massive issue; the average age of a mental health nurse is 55, and, I believe, rising—this is going to lead to significant issues in the immediate future. We can have meetings and conversations and make plans, but these will be redundant unless we have staff on the ground.

Perspective: Clinical nurse consultant; regional health

6 6 I've seen a lot of graduates come into the mental health space and then exit over a couple of years. There are a lot of people that leave, sadly. I've really found retention of staff, particularly graduates, is something we've struggled with. I don't think it's got any worse, I think it's just something we haven't managed to fix. We need an increase in workforce, and I believe that the lived experience workforce is one where we'll be able to recruit a good number to bring into the service.

Perspective: Consumer and peer worker; regional PHN

For 7 years I sat as a volunteer with the police, to provide support internally to help them in terms of their own mental health. It was just heartbreaking to see the level of workplace stress there. The effects of mental health on just that one little diverse community group. We all need the education to see through a similar lens, and not one community group needs to feel more responsible than the other. Otherwise, the system doesn't work. It becomes out of kilter, so we then have the mental health crisis we have.

Perspective: Carer with lived experience of family trauma

6 6 The mental health and wellbeing of police is important, especially frontline police dealing with so many varying incidents in the community. Our police are consistently exposed to disturbing images and behaviours, and take on a variety of roles based on the circumstances. Some things that I've seen have been quite horrific and it can't not affect you in some way psychologically over time.

This goes along with feelings of being a support service to people in the community, because there are no other services available for people we are dealing with. The number of mental health incidents we are attending in the community is increasing exponentially, with people threatening, self-harm and so on.

Anecdotally we have more police now struggling with their own mental health. This can lead to work stresses, with members having taken time off work because they are dealing with the fact that they seem to have these extra responsibilities that they weren't trained for. That said, we are now incorporating mental health modules into police training, which is a positive.

Perspective: Police and mental health

Diversity in the workforce

One conversation explored the need for people to identify with their health professionals to trust them and get the most out of the treatment available. From this perspective, there is a need to recruit more males, and more people from diverse communities into the mental health workforce.

People need to trust in order to share their vulnerability and benefit from health services. For that to happen, you need to be able to identify with the health professional, to feel that they can not only understand but also relate to what you are experiencing. The basis of peer-to-peer support is that people can identify with each other. This needs to be reflected in the health professional workforce, too. We need greater diversity in the mental health workforce, more gender diversity and more reflections of other identities too. Men need to find more men working in mental health and talking about mental health in the community.

Perspective: Men's preventive mental health and mutual support

Training and support for the future

Training and support can increase the understanding and confidence of the mental health workforce, leading to better outcomes for service users and the staff who provide those services.¹⁵

6 6 When you are just starting out in psychiatry, you are so afraid of making a mistake, of getting things wrong. Your focus narrows down to the tasks you need to do to be a doctor, and it is so easy sometimes to leave your humanity at the door.

When I first started working in public health in 2010, my focus was on getting the diagnosis right—fitting people into the right category and the right treatment. Now, I hope I take a more flexible approach where I make the category fit the person so they can access what they need.

Diagnosis isn't helpful unless it helps the person. I feel frustrated when I see young registrars working from a 'checklist and diagnosis' perspective with no real regard for the individual person they are working with. My other concern is when they seem to take a position of authority because they are the doctor and forget that it's a real person's life that they are affecting. And then I think that I was probably just like that when I started. Perhaps we need to feel a solid grounding in the textbook knowledge, in the checklists and diagnoses, before we can take a step back and start to see the whole picture. In a way, a person-centred perspective is something that we have to learn alongside what I call the technical side of psychiatry.

Perspective: Psychiatrist; public health

6 6 When I was studying for my master's degree, I was taught that BPD cannot be treated. That is a view that is 50 years old, and it was still being taught in the past 10 years. Our training continues to perpetuate myths about mental health. We need to let go of the way things have always been done, and embrace the evidence of how they should be done. Education is the first step, and public health is terrible at re-training staff and keeping itself up to date.

Perspective: Lived experience, peer worker and therapist

In the conversations, 3 initiatives were highlighted that may equip people to partner in the delivery of person-centred care and engage in work in regional areas.

The initiatives would provide a rural training pathway, increase the use of co-produced training, and increase support for frontline clinicians.

A rural training pathway

6 6 From a workforce perspective, I think we're now seeing a lot of new grads being quite interested in mental health and seeing a career pathway in mental health, as opposed to it just being part of a range of skills that they think they need for a CV.

Training, for a long time, has been very metro-centric, but we've seen recently some changes in regards to rural training pathways that I think need to be continued to be developed. The rural training pathway with Mat Coleman [Professor Coleman, the RANZCP Rural Psychiatry Roadmap 2021–31] is only something that's really been announced this year. One of the things we've always talked about is local country kids having the opportunity to be educated and trained in a country space, as opposed to constantly being pulled into a metro environment.

From a WA perspective, there's emerging linked-up thinking around how we can offer junior doctors experience across all the different specialties of psychiatry in a way that still keeps kids in the country and gives them that really different experience.

Perspective: Allied health and nursing professional; regional health

Co-produced training for frontline workers

6 6 The Undergraduate Certificate in Mental Health at Monash University was developed and offered under the Australian Government's Priority Places Package and access was therefore time limited. The last cohort of students will complete the course in 2022. This was a co-produced initiative that helped students to understand mental health from a lived experience perspective. Most students have been emergency service workers, police, child protection and psychologists. More than 1,000 people enrolled. They really welcomed the lived experience content of the curriculum. This has been such an exciting project. We had to pull it together in a hurry, but the response from students has been wonderful.

Now that we have tried having a separate certificate, we have realised that we need to insert this material in every health care qualification, rather than making it an optional and separate certificate. We still don't give mental health professionals any suicide prevention training. There are still many GPs who have not trained in suicide prevention or mental health. We have a lot of gatekeeper programs, but we have been missing out on training our essential mental health workforce.

Perspective: Living experience, carer and suicide prevention consultant

Supporting frontline clinicians

6 6 The challenge is to keep supporting clinicians, so they don't either feel disheartened because all they're seeing is revolving door crisis management, but they're also not taking this on to a point where they're feeling overloaded and at risk themselves.

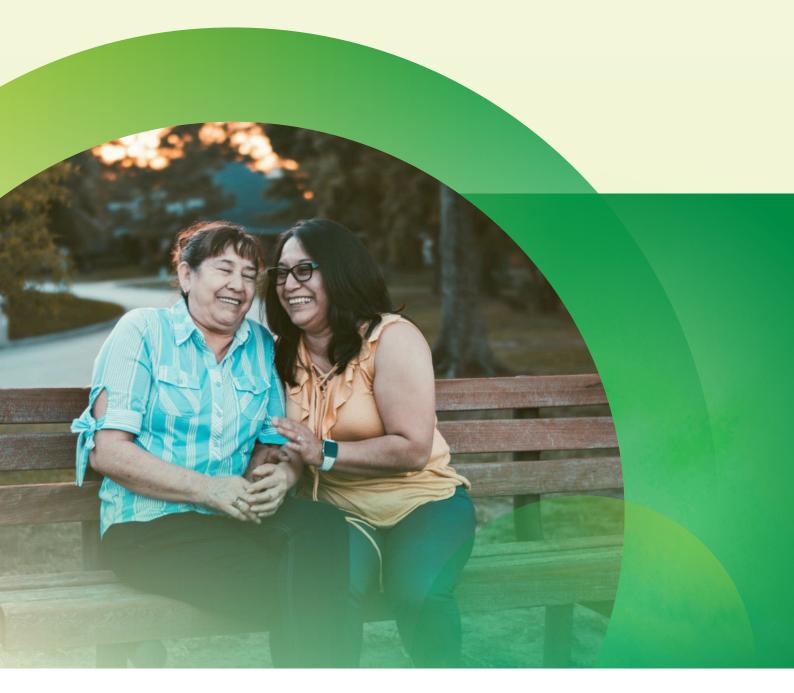
We've trialled a GP psychiatric support line. What we're trying to do is build capacity within the existing workforce. At the moment, that's purely around supporting GPs, but it could be expanded to support NGOs [non-government organisations]. We've found, from a country perspective, that GPs are more likely to feel comfortable doing a review themselves (rather than referring to our service) knowing that they've got access to a psychiatrist for a quick 5-minute conversation to talk about symptom or behavioural management.

Perspective: Allied health and nursing professional; regional health

Findings: exploring experiences

Chapter 7

Social determinants of mental health



7. Social determinants of mental health



The social determinants of health were coming to the forefront of thinking about health in the years just before the Commission started work, through initiatives such as the World Health Organization Commission on the Social Determinants of Health.

A wide range of social conditions had been shown to affect mental health, including insecure housing, unemployment, low income, child abuse, lack of social connection and discrimination.¹⁸

Local community issues—including socio-economic conditions, the physical environment and crime rates—were also found to affect mental health.¹⁹

The first chair of the Commission, Alan Fels, noted that the mental health system at that time was not designed to address the wider issues that affect mental health.⁴ The <u>Contributing Life Framework</u> developed by the Commission in 2013 addresses 5 domains. Only one of these domains directly relates to health services; the others address safety and security, social connection, meaningful activity and thriving.

Conversations

Conversations explored the extent to which social determinants of mental health are now recognised, and the progress that is being made towards integrating social support with health services.

Participants had experienced an increase in awareness of the relationship between social problems and mental health problems.

6 6 There is now a lot more emphasis on social determinants of mental health. We can't expect people to prosper without the essentials of life.

Perspective: Lived experience representative and peer worker; PHN 6 6 Mental health is complex, and it goes hand-in-hand with physical health and social determinants like employment, school etc. I think that on many fronts we've come a long way in terms of recognising the intricacies and nuances of different kinds of mental health.

Perspective: Lived experience representative, researcher and clinical psychology registrar

However, this understanding had not made an obvious difference to the way mental health services are delivered. People are identified after they develop mental illness, and then are referred to a health service that lacks the resources to address social needs.

There is still an emphasis on clinical services and a clinical approach. The result was experienced as a 'band aid' approach that helps, but does not provide sustainable improvements in mental health. More coordination between clinical and social services and a broader approach would make a real difference.

Reliance on clinical services

6 6 My work feels like dealing with the downstream effects of life events that have happened to people that changed their mental health. It feels like a flood that we can't stop. If we could just help people to deal with the messiness of life. If we can help them to find safety, housing, income security, and connection with others, then it's possible that their need for medical and hospital services are going to be less pressing.

For so many of the people I work with, their mental health is not their top priority. Finding a way to feed their child or pay the rent is the top priority. People need a safe place from which to deal with their mental health issues, and that isn't always just in a mental health service.

Perspective: Psychiatrist; public health

We still have the determination of a 'mental health client' so therefore they're your responsibility lock, stock and barrel. You have to either fix them or manage them and maintain them. That doesn't take into account the social determinants of health. I think all we end up doing is we band-aid and we put out fires in the very short-term. I wouldn't even say medium term, because ultimately, we're not fundamentally changing the social determinants of health and social justice factors that a lot of our clients face or have faced that have led them into that space—not all clients, but a significant number.

I think it's interesting to think about why we're seeing such a steep increase of crisis presentations, including suicide, self-harm and eating disorders. I think, more and more, we need to think about the social aspect that are causing this; it's not rocket science by any stretch.

Aboriginal people make up just under 10% of the overall population, but they make up over 25% of our client population. It's a really strong indicator that there is something fundamentally wrong. And, as a mental health service, all we're primarily doing is just trying to hold that client together as best we can.

When you look at what the client actually needs, there's nothing available in the system to address that. There's a huge reliance on a medical, clinical model to solve a social issue. I think this issue has been better recognised over the past 10 years, but I don't see a lot of significant change to address that. There's a clinical role, but it's not a clinical solution.

I think we really need to understand what that means at a much broader level, and I think that, in part, comes back to local commissioning. We're still trying to build beds and we're still trying to cobble together clinical services to try and address what is otherwise a cultural issue and a social issue. That requires generational change, it can't be fixed in days. It actually has to be fixed in years and you need policy and strategic thinking that's prepared to think across generations, not in 1 to 2-year cycles.

Perspective: Allied health and nursing professional; regional health

Working together

The solution was identified as enabling social services and health services to work more effectively together. There was agreement across the conversations that we need a broader concept of mental health that integrates social and health issues, recognising that these areas are, to some extent, mutually dependent. This level of integration needs to be built into the design of services from the beginning. Achieving integrated regional planning and service delivery was a priority of the Fifth Plan.

This is a radical change in the way that we currently organise mental health care, and participants recognised that it had far reaching implications for policy, planning and funding. Services developed and integrated at the local level were experienced as most likely to meet needs in the context of local community issues and resources. 6 6 You can't silo people's lives. We live the whole experience of all the different factors that impact on our life and our opportunities. When we look at things at a group level, we lose sight of the complexity and difference of people's lives.

Intersectionality offers a way to profoundly change social inclusion. We don't have a good understanding of how to integrate this into how we design and deliver services. It still offers us the best path to achieving long-lasting change. It really requires us to rattle the system.

Perspective: Consumer and lived experience worker

C There's certainly been improvement in the relationship between the services, so we're not working in silos as much as we used to be. There's a lot more interaction and conversation going on, and negotiation between us, and a bit more understanding of what the individual services do. I've been in this role for about 6 years now. I've certainly seen an improvement in that area.

Perspective: Police and mental health

We tend to still put our buckets of money in specific silos. Money's really there once you've got a diagnosis and you're acutely unwell. We know that there's a lot of contributing factors that we could work on earlier, like children growing up in safe houses, no domestic violence, good education, the basic tenets of building a good foundation for your life. We all know it, but I'm not seeing a joined-up way of how we're approaching that. We need to expand—the National Mental Health and Suicide plan needs to go broader.

Perspective: Consumer and peer worker; regional PHN

Housing security

In the conversations, secure housing was raised as a current issue affecting people's mental health.

The safety, stability and security that comes from having a home is fundamental to optimal mental health and to leading a contributing life. The intersection between homelessness and mental ill health is a key concern for the Commission.

In 2017, the Commission supported a national consultation on housing issues in relation to mental health conducted by the Australian Housing and Urban Research Institute. The review identified a lack of affordable, safe, and appropriate housing for people with lived experience of mental ill health. Although housing, homelessness and mental health are interrelated, they are separate policy areas, and this contributes to poor housing and mental health outcomes.²⁰

Housing security has become a priority in a decade during which people have been affected by COVID-19 health directives, loss of homes in floods and fires, and an increasing lack of low-cost housing stock. What used to be valid alternatives of private rent are just no longer an option for people who are living off the disability support pension or youth allowance. They're just priced out of the market. The first thing I would change is improve housing, and housing affordability. I would increase Centrelink payments for a whole range of things, including disability support pension, but also other kinds of income support that people with mental health problems have issues with.

Perspective: Allied health professional; forensic and justice systems

COVID was a bit of a winner for us—a lot of people came out to regional Victoria because we didn't have the lockdowns, so that was one positive out of a very hard couple of years. Hopefully, we can keep them. But there's also some negatives—the rental space is just through the roof here locally, so there's a lot of locals unable to find an affordable rental anymore; they have to move further out of town. Are they able to get the care that they need if they have mental health concerns or chronic illnesses? No.

Perspective: Consumer and peer worker; regional PHN

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Insecure housing contributes to adverse mental health outcomes for everyone, and more so for those living with mental illness. A fundamental human need is that of safe and secure shelter. If we cannot meet this most basic of human living requirements, we will never achieve other fundamental needs such as a sense of belonging, self-esteem and achievement.

Professor Wendy Cross, Commissioner¹¹

Findings: exploring experiences

Chapter 8

Prevention and community connection



Prevention in mental health is clearly linked with improved long-term outcomes across all aspects of life. A Spotlight Report to the Commission that reviewed attitudes to mental health found that Australians believed that approaches to mental illness should be something more than 'fixing problems'. People expressed the need to focus on prevention as well as treatment.⁷

6 6 I think really working on prevention services is one of the next big priorities in working to reduce waiting lists. I think the 2 are connected. If you work on prevention, then you have done some of the work to reduce the demand for other services.

Perspective: Lived experience representative, researcher and clinical psychology registrar



Conversations

The conversations linked preventive activities with smaller waiting lists and better access to health services when these are needed. Building community and developing the life skills needed to navigate the messiness of life were seen as vital for prevention and at any point in the recovery journey. The current approach to health services as individual and timelimited were contrasted with the long-lasting value of local relationships and healthy community.

A dominant theme in the conversations was connection, exploring the ways in which we all need to feel part of a community.

We need to focus on connection. We need to be more connected—not just mental health services, more connected in all the areas of life. Connecting with skills, with relationships so that people can deal with the messiness of life, with the real world that is full of uncertainties. Everyone benefits when community support and health services work together.

Perspective: Psychiatrist; public health

Integrating informal peer supports into the network of mental health resources and investing in prevention programs that connect people and develop life skills were seen as essential to improving mental health. For this level of face-to-face connection, these solutions need to be developed and delivered within the local or identity community.

The conversations explored 2 grassroots initiatives that provide opportunities for intentional community support between peers.

The first—the Men's Table—started as a personal social group, and developed into a support group that is all about understanding the importance of social connection, intentional sharing and non-judgemental listening for men's mental health and wellbeing.

The second—the Silver Fox initiative—started more recently in the context of the growing community conversation about mental health and the difficulties people experience trying to access services. Both found that people need a community and someone to listen to them.

The Men's Table I realised there was no community for me

6 When we started Men's Table about 12 years ago, mental health just wasn't a thing we thought about. I know I was coming from a place of pain and challenging social issues. I only realised later that I had some undiagnosed mental health issues.

Being at a Table helped us to develop more awareness of the struggles that men experience. I always understood the value of a having someone to talk to, a good conversation. Men's Table has helped me see the therapeutic value of having someone safe to turn to for that conversation. 'I am not alone' has been a consistent theme at Tables. It's the big realisation for many men that others are also having a tough time. Having a real community keeps coming up again and again.

For whatever reason, many of the men we talk to are just not going to access the health system. They just need a community and somebody like them to listen to them and understand. We have learned that there are lots of people dealing with trauma that affects the whole of their life. They don't make the connection between stress and social difficulties and mental health. If mental health was brought up, half the men wouldn't have come to a Table.

One thing that stands out is how much attention in the health system is focused on the individual. Everything is about 'fixing' the one person. We don't see a lot of evidence of building healthy communities, especially in suicide prevention. There is a huge gap in the way we frame support when we only look at individuals. We pathologise the individual. We label them as 'ill'. This comes straight out of the mental health system. It isn't a health system—it's a sickness system. Let's put in place things that help people to be mentally healthy. They say it takes a village to raise a child. Why should it stop there?

The recent Australian Men's Health Forum piece around suicide in Tasmania highlights starkly that male suicide is largely down to social determinants rather than mental health issues. The stats show that it is life's stresses and strains that will often lead to a man suiciding.

We need more men in the community, in the health system and in society talking about the bumps and the scrapes. In the long run this would be a far cheaper and more effective way of helping men and the people around them to have a better life.

Sharing adversity seems to act like a kind of glue for the Table groups. Once they have shared their vulnerability, the bonds form quickly and they begin to form a community. Community is long-term. It isn't a program that you attend for 6 months or a service that's funded for 2 years. Community is with you for the long haul of life. Community shouldn't end when the current crisis is over. We build a resilient community to help individual resilience. This is a life journey that we walk together. There is a clear ripple effect.

Men who share in community also have better relationships with their families and partners, with their male friends and their colleagues. The influence of community is broader than the small group.

Perspective: Men's preventive mental health and mutual support

The Silver Fox Initiative

A safe place where we are in this together

6 Silver Fox organises walks and runs that bring people together for exercise and fun. We give people a chance to be themselves. We don't want to be the person who solves problems or makes decisions for others. We are the start of the conversation. We give people a safe place to express that they are having a bad day knowing that they won't be judged.

Over the past few years, mental health has become the number one priority in my life. I am seeing people struggling with mental health challenges that I just wouldn't have expected to be having these difficulties. We offer friendly support for people who need to connect with mental health services, maybe for the first time. We can go and sit in the waiting room with them, have a cup of coffee afterwards and make it feel like a normal part of life.

GPs and psychologists just can't see everybody. People are falling through the cracks and getting more isolated while they wait for months for appointments. It is important to have something to support you and connect you with others. Any kind of community group would probably work.

The more we create opportunities to sit and talk, the more we work together as a community, the more success we will have with mental health. We need to encourage more connection and conversation. When people see that it is okay to chat about mental health, not just today but every day, there is less chance of suicide or increasing depression.

Perspective: Community peer-to-peer support worker

Spotlight Veterans' experiences

The Commission's Review into the suicide and self-harm prevention services available to current and former serving Australian Defence Force members and their families found evidence of good practice and positive outcomes. But participants also identified areas for improvement to systems, services, beliefs and culture. Although many people who had used the services reported a positive experience, there were also poor experiences and feelings of cynicism, distrust, frustration, abandonment and loss.

The experience of seeking compensation and of other administrative claims processes can be complicated and prolonged, contributing to increased distress and suicidal behaviour.

In the following conversation, one person reflected on their experience as a veteran, and the need to develop community and identity after leaving the close-knit military community.

When I was discharging from the military, my mental health had gone to s***, yet, as a digger, I was also informally supporting the mental health of the supervisor of a soldier who had died by suicide. I was lucky, though, because I had some really good support from my partner who helped me discharge from the military and navigate the DVA [Department of Veterans Affairs] 'stuff'—which is an incredibly difficult process to go through.

I was incredibly lucky, though, because, after discharging, the DVA paid for me to go to university while also providing me with a pension when I was an undergraduate. I also had lots of support and case managers for the whole time that I was studying. Without that support and good case management, I wouldn't have gotten as far as I have. I'm here today because of those key supports. This process [discharging] can be hard to do well, but when it's done right it really sets you up for success. I was definitely one of the lucky ones. Now, I'm completing my clinical PhD in Psychology. From my perspective, military members have such close bonds, we're willing to fight and die for each other, right? When we leave the military, there can be a huge loss of identity. What is there to fill that void? For the entirety of our service, we've been a 'soldier first' and everything else second. We've been told we're not civilians, and many veterans don't believe they can ever be civilians again.

Therefore, for some veterans, discharge may be the most significant life transition they will experience, and it can be associated with so much loss—loss of identity, who you were, who you will become. I believe such uncertainty can lead to transition-related mental health and wellbeing challenges.

As part of my PhD, I'm investigating how we might be able to measure identity loss as a means to screen for veterans who may be likely to experience transition difficulties. I believe that with the appropriate support and allocation of resources, we can empower the veteran community to support contemporary veterans as they discharge. I believe a strong and representative veteran community will help newly discharged veterans establish some good attitudes and norms around help-seeking, and support mental health and wellbeing.

I can't think of a population that would benefit more from peer workers than military populations—something which I do not think is currently being used to its full capacity. I believe there should be veteran mental health peer workers in every veteran ward.

Perspective: Lived experience, military veteran, peer worker and provisional psychologist

Findings: exploring experiences

Chapter 9

The mental health system



In complex systems, changes experienced at the individual or community level (such as better mental wellbeing) depend on changes within the system.²¹ Leadership, planning, funding and protocols form the foundation for the mental health system. The decision-making and administrative components of the mental health system are as influential as the practices of frontline services and health professionals. Since 2016, several key reform initiatives have changed the way the mental health system in Australia is organised. These include the:

- introduction of PHNs
- introduction of the NDIS
- Fifth Plan
- National Mental Health and Suicide Prevention Agreement.

In 2018, the Commission noted that the fact that these initiatives were all occurring simultaneously and were interrelated added to the complexity of implementation, and that it would take time before consumers and carers experienced sustained change.¹⁵

Conversations

The conversation about the mental health system was wide ranging. Participants had experience with PHNs and the NDIS. The discussion identified inequities in the current system, and explored the impact of various types of regulation and administrative requirements on what mental health services can achieve. People saw structural barriers impeding major changes to the mental health system, including approaches to planning and funding, and a lack of consistency in the implementation of reforms.

The current mental health system is not well integrated, and this affects the implementation of reform initiatives and the way that people experience services. Participants saw a need for commitment to integrated policy, planning, funding and frontline services. The lack of commitment to genuine prevention and early intervention was also noted in conversation (see Chapter 8: Prevention and community connection).

Participants said longer-term funding was needed to support sustainable services in communities, seeing this as a way of supporting the mental health of communities and retaining a skilled mental health workforce in regional and rural areas. They also identified the need to learn from the past and to use existing resources and understanding to consolidate progress.

The structures underpinning the mental health system

A priority in the Fifth Plan was to make sure that the enablers of effective system performance and system improvement are in place. The conversations showed an increased awareness of these enablers and the impact that they have on the effectiveness of reform. They were understood to include legislation, policy, plans, funding models and protocols at the national, state and local service level.

The structure of the mental health system was seen as directly contributing to inequality in access to mental health services for rural and regional areas and for people on low incomes. The conversations also noted inequity for people with specific diagnoses and that some groups are better served than others.

Working with clients continues to be a joy of my life, yet when I see the system, I feel greatly distressed. There has been quite some investment [over the past 10 years] with more options available now via Better Access, NGOs, NDIS, but it's hard to get them to work together as they are all too busy and not well integrated.

We need to spend more time to understand how these systems work together. We have a system that is highly inequitable—effective in pockets, but large areas which are inefficient. For those who have resources, they can get higher-quality care, or for some who have certain health problem—like early psychosis or eating disorder you may do well in the public system, especially in some geographical areas.

There is financial inefficiency as well. GPs are incentivised to place people on [mental health care] plans, which may or may not be followed through and there may be no outcomes. This costs taxpayers money and takes up a scarce resource. In the public system, there is underservicing, as the system is so busy with people with serious illness.

Perspective: Psychiatrist and researcher; public and private health

6 In 2021, I was engaged by the State Mental Health Tribunal to deliver a presentation on why people with BPD [borderline personality disorder] should not be sectioned. They heard it, yet in June I had to fight to get myself away from that system and avoid more forced care. My clinicians were on my side, and they did everything they could to help me. Sadly, it meant that for many involved in my care, the experience scared them, and they are now incredibly disillusioned and fearful of involving the system again. This isn't helpful for any of us. The system routinely pays us for advice, and then they ignore it.

The impact of policy

The translation of policy into practice can have unintended consequences. Policies that address one area of concern can negatively affect the impact of reforms in other areas. When designing new policies and services, policymakers must be aware of the impact that the new approach will have on other service systems and on the people who use those systems.

The conversation about policy repeated the theme that the mental health sector is broader than health services.

What has changed in the past 10 years is the new state Mental Health Act, and that Act has gone from primarily a risk-based Act to a capacity-based Act. And, with that, the tribunal itself got much bigger and much more expensive. And there has been this quite big investment into that kind of field. I think it gives people confidence that there's a rigorous approach taken to involuntary treatment and involuntary care, but, by the same token, I think it's pretty difficult still if you're the consumer and you're up against doctor, case worker, nurse, system ... and even if you have an advocate, they're not allowed to have a look at your file anyway. It's a pretty big mountain to try to get over.

Perspective: Allied health professional; forensic and justice systems

6 I think there needs to be accountability for community mental health at all levels and across all government departments. To say that you are concerned about the mental health of a group—for example Aboriginal and Torres Strait Islander communities or the LGBQTI community—and then initiate policies or debate in other areas of government that increase the trauma and distress of those groups makes no sense. Until we recognise the pain that the whole government system can inflict on people who are marginalised, we cannot solve mental health issues.

Perspective: Consumer and lived experience worker

The impact of beliefs and protocols

Research has shown that beliefs embedded in the system—such as reliance on diagnosis in a medicalised model of care—act as barriers to the introduction of reforms.²²

6 6 I understand the difficulties working in a deficitbased system. Health professionals are impacted by the pressure to conform to the system. The people (health professionals) are not the problem. The system is the problem.

Perspective: Lived experience, peer worker and therapist

Everything is very system driven. There is no help until the problem is already well established.
Staff take an attitude of 'we can't do that' without exploring alternatives. The person must fit in with their system.
I know that diagnosis can help people to access services.
It shouldn't be used to exclude people from the services they need.

Perspective: Carer peer worker and advocate

Over the years, my practice has evolved. I take a flexible approach [to diagnosis]. I make the category fit the person so they can access what they need. Diagnosis isn't helpful unless it helps the person. One of the important parts of psychiatry is working out why this person and why now. Illness is only one part of the picture, there is so much more to each person's life.

Every person will experience mental illness differently. Diagnosis makes them all appear to be the same, but they aren't. We are sitting in an uncomfortable space where you must justify your choices, possibly to the coroner. There is a push to make the safe textbook decision. We are really bad at getting the balance right between managing risk and still responding helpfully for the person.

Perspective: Psychiatrist; public health

The structures underpinning the mental health system

The impact of funding

The way in which funding is structured has an influence at multiple levels—from the need to make a specific diagnosis to access services and medications to the impact of funding models on the viability of local services. Short-term funding and a focus on pilot projects were identified as significant barriers to developing effective local mental health services.

One problem with reform to date has been that new initiatives are added on to the existing service system. Flexible approaches are tied to inflexible funding, performance measures focus on investment rather than individual life outcomes, and hierarchical decision-making about program funding distances decisions from the people and communities in need.

A lot of funding goes to new ideas and is time limited. PHNs are limited by short-term funding. You can't set up a viable service with only 1 to 2 years funding. People just aren't there long enough to bring about real change. You need around 9 years to really change things. When funding changes every couple of years and staff, including leaders, move on as well, there isn't enough momentum to keep the change going.

Perspective: Consumer representative and peer worker

6 6 Funding cycles are too short to help people understand what works, to think properly about what is needed. They are too short to keep staff engaged. People move on and knowledge is lost. Lots of good work is not taken to scale.

Perspective: Lived experience representative and peer worker; PHN

There seems to have been 2 parallel processes. On the one hand, we are listening to lived experience more, and promoting responses to diversity, which opens all sorts of new ways of doing things. On the other hand, we are getting more restrictive approaches to funding, tighter budget margins, leaner models, and more rigid accountability requirements. Accountability is important, but applying business models of accountability doesn't fit with trying to develop new ways of working that respond to diversity.

We need investment in development first. It is really hard to change government ways of doing things. We have to change radically if we are going to re-think mental health. If we just go back to the way we know, the way that makes us comfortable, then we are going to get more of the same. We need to build in reflective processes that will help everyone, including governments, think about the impact that their way of doing things has on others and on the mental health system. We haven't critiqued our government systems enough to see if they are fit to support the mental health system we need.

Perspective: Consumer and lived experience worker

Because of current funding arrangements, we see a lot of short-term fixed funding for NGOs, where they spend a lot of time (especially in country settings) worrying about the sustainability of their service and being able to keep clinicians and their workforce engaged.

They seem to be in an ongoing short-term funding application and review process that becomes more of a distraction for them than actually providing the service, and you can see that at certain times of the funding cycle.

I think there's nothing more devastating to a client or a community when services come and go without any understanding as to why that's happened, why did that service wrap up and disappear? The community never really gets to understand why. The client then gets referred on to another agency that's not really agreed to take on that client. There's still that disruption. We need to understand that there's long-term care required for some clients, and change can be really unsettling and frustrating for them, and has an impact on their willingness or ability to engage in their treatment.

Perspective: Allied health and nursing professional; regional health

6 6 One of our greatest bugbears is that we just don't see true commissioning at a local level or at a situational level. What we still see is state and even federal commissioning that probably doesn't take in all those specific needs that you can see replicated in other countries.

The UK Trust system, for example, is very much able to set up, fund and identify what services they need based on their particular population's needs and the local governance. We're still a little bit more block and tackle than that. When you've got federally funded 'commissioning' and identification of priorities, it can sometimes feel, at my level, quite a dislocated, distant process. It feels very far away. That may well be because we are operating in a state public health system.

Perspective: Allied health and nursing professional; regional health

The impact of inquiries

The Fifth National Mental Health and Suicide Prevention Plan was welcomed as a significant development. With the implementation of this plan, the Commission took on the role of reporting annually on planned actions and performance against identified indicators.¹⁵

The conversations were somewhat sceptical about the real impact of inquiries and national plans. People echoed a comment made by the Commission in 2012 that Australia is very good at identifying need, but not so good at matching the services to meet that need.²

6 6 There was a significant amount of work done before the Commission was established in 2012—the Burdekin report in 1992, the 1994 National Community Advisory Group report Let's talk about action, the 23 'big issues' identified as a result of the 2000 Consumer Day, and the 2005 MHCA [Mental Health Council of Australia, now Mental Health Australia] Not for service report. All reports expressed the failures in the mental health system and the need for change. How many of the issues raised then have been addressed? Some progress has been made, but there is still a long way to go.

Perspective: Consumer representative and peer worker

C The Productivity Commission report was interesting. It shows us a lot of things we already knew. But I haven't seen too much work come out of that. In comparison, with the Royal Commission we saw an immediate sort of people jumping on it and saying "okay this is what's going to happen within our state so let's get on board".

That's all well and good, but the timeframes surrounding some of the rollout of these Royal Commission recommendations means that there's just so much activity happening in the sector that it appears that the left hand doesn't know what the right hand is doing on many occasions. It's a lot to keep abreast of all the change. I think while it's great to see a government want to really make change, we do have to be mindful that there's only so much that people can take on board at any one time. And that some of these recommendations actually will take a significant period of time to create positive change.

Perspective: Consumer and peer worker; regional PHN

Primary Health Networks

PHNs started to integrate and coordinate health care at a regional and local level in July 2015. They have responsibility for local-level action in mental health and suicide prevention, and for commissioning all regionally delivered Australian Government Department of Health and Aged Care mental health programs.

The PHN model—with its emphasis on local development and coordination and engagement of lived experience was experienced as a positive change in the structure of the mental health system. However, lack of consistency between PHNs in their capacity to address mental health issues and their engagement of a lived experience workforce were seen as limiting their effectiveness.

Overall, there was a feeling that PHNs were not sufficiently resourced to address mental health needs, with most funding being allocated at a state or national level.

6 6 The introduction of PHNs has made a big difference in mental health. They can redirect funds where they are most needed in each region. They are bringing primary and secondary health services and non-government services together to work collaboratively. This helps to meet the needs of people who would otherwise have fallen through the cracks.

PHNs can really work at the local level, and involve people with lived experience. Collaboration at this level has a huge impact. It was a smart move to put control of funds into the hands of a neutral group that don't deliver services.

Some PHNs are now moving into service provision, and I wonder if that will change the value of what they do in bringing the whole sector together collaboratively. The problem with PHNs is one of consistency. They aren't all making progress with mental health to the same extent. Some regions are very big, and the PHN is going to find it hard to get involved at the truly local level.

Perspective: Consumer representative and peer worker

6 6 PHNs still have unrealised potential in supporting serious change in mental health. The idea of regional planning and collaboration is good, but it hasn't been done as well or as consistently as it could be. The larger needs of the health system dominate and limit what PHNs can do. The big services and programs sit outside the scope of what PHNs can really influence. They only have a small percentage of the mental health budget. A lot more goes to perpetuating the existing system of acute care, and this keeps risk as the primary reason for providing care.

I have done a lot of work around peer work and participation through PHNs. We have been looking seriously at how to enhance lived experience representation and participation, and how to develop and support a peer workforce. With a genuine focus on lived experience involvement, there is real potential for change. I think about one-third of PHNs have employed people in designated lived experience positions. It is important to embed these roles within the system and then support them to network across the whole system. Coming from a lived experience perspective makes it possible to work across all the different spaces in the health and social systems. This can overcome silos, and start to bring the system together more effectively.

We really need a national approach to developing a lived experience workforce across all PHNs. We need a national framework and leadership to make sure this is effective and consistent across all regions. The national PHN Mental Health Lived Experience Engagement Network is doing strong work in supporting and developing the peer workforce and strengthening consumer and carer engagement in PHNs.

Perspective: Lived experience representative and peer worker; PHN

National Disability Insurance Scheme

The decision to include people with a psychosocial disability in the NDIS came about as a result of consultation with people with lived experience, and the recommendations of the Productivity Commission in 2011, but the design of the NDIS was not initially informed by the needs of people with psychosocial disabilities.¹⁴ Advocacy from the Commission and others promoted inclusive processes to support people with psychosocial disabilities in the NDIS.⁴

Currently, participants with a primary psychosocial disability represent the third largest cohort in the NDIS. As such, the NDIS is now a significant component of Commonwealth and State and Territory Governments' investment in mental health.

Including psychosocial disability in the NDIS brought new opportunities for people with severe mental health issues. However, in rolling out and administering the NDIS, the NDIA has faced a range of challenges in implementing the Scheme to deliver good outcomes and a good participant experience for all people with a psychosocial disability. The NDIA has expressed that it is committed to improving the NDIS experience of people living with psychosocial disability and continues to implement enhancements for people with a psychosocial disability. Many significant reforms are underway, including implementation of the **NDIS Recovery Framework**, and it will take time for these changes to be reflected in participant experiences such as those described in this report.

Participants experienced the introduction of the NDIS as a big change. Benefits were seen in the support-worker model and in the ability to choose the type of therapy outside the limited scope of approved Medicare Benefits Schedule psychological strategies.

Overall, however, the participant experiences were that the system was not well designed to meet the needs of people with psychosocial disabilities. Many barriers were experienced to accessing services, and some service providers were not sufficiently skilled in mental health. The NDIS is relying on limited mental health clinical resources to assist people through the assessment process, taking scarce resources away from the provision of mental health care. There was an impression that the difficulties in accessing the right kind of support were getting worse over time rather than improving. This was seen as partly due to more restricted NDIS protocols and partly due to the closure of local support services that were no longer viable under NDIS funding arrangements.

A key issue was the fact that NDIS is a deficit-based system in which a person is expected to prove permanent disability.^a This is at odds with a mental health recoveryfocused approach. One conversation noted the need for services that integrated disability support and mental health services.

NDIS has been a big change. I think it's been detrimental for a lot of people. I know some people have got good packages. But plans aren't as comprehensive as they once were. I feel that gap that we were trying to mend has just become a chasm now. People are falling in and not able to get a service because all Commonwealthfunded programs were rolled into the NDIS, and there isn't much else out there available for people. It's changed the sector. A lot of service providers have gone, those organisations have closed. Where are those individuals now receiving their care from without an alternative Commonwealth-funded program to turn to? It had great promise at the start, but I believe the changes and the chipping away of it over the past few years has seen it not reach the aims and the intent that it originally was devised for.

Perspective: Consumer and peer worker; regional PHN

6 I know that things are challenging in terms of NDIS, and the support that families receive. I just know there are so many barriers to accessing services. I can certainly speak to my own children's experience in terms of that. Various times they have needed mental health support, but have not met criteria for certain support services. It's just a challenging space and the long waiting times for NDIS packages.

Perspective: Carer with lived experience of family trauma

a. The NDIS Recovery Framework seeks to address these well-known implementation challenges. It has been endorsed by disability ministers and is being implemented progressively throughout 2022–2025.

National Disability Insurance Scheme

6 6 The other thing that I find really sad about the NDIS is that it's not a strength-focused service—it's very deficit focused. You have to always show your functional impairment. And from a person that's come from that space, the time where I was on a disability support pension, being case managed and all the conversations were around what I couldn't do, I started to believe that I couldn't do anything.

It wasn't until I got into programs that started talking about recovery, building on your strengths, that I was able to return to work. My fear is that we've lost those programs. Who's out there doing that recovery work, and the strengthsfocused work? It doesn't fit the NDIS model. It doesn't make sense to penalise people for an improvement in their state. It's been backwards.

Perspective: Consumer and peer worker; regional PHN

6 6 NDIS is a space where the providers are not always as skilled in mental health as perhaps they could be. The quality is a bit hit and miss. On the other hand, the way that the NDIS works is so different to the way mental health services have worked in terms of funding packages and choice of providers, and that is really positive. I've seen lots of cases where there's a support worker model going in and sometimes that can only be for 2 hours a day, but it really changes it from someone having to need institutional care to being able to live independently. That kind of support is really positive, just very practical, daily living support.

Perspective: Allied health professional; forensic and justice systems

6 6 NDIS has come with its challenges. As more and more people become interested in the NDIS as a viable option for them, it's falling back onto clinical services to assist that person through the assessment process, which is unfortunately a completely burdensome process, long, drawn out and paperwork-heavy.

At the end of the day, it's still a complicated system for clients to navigate, and they often will need varying levels of support to do so. We don't really see a lot of capacity or clinical expertise for this in the community or secondary space. In our Child and Adolescent Mental Health Service, a large proportion of our psychiatrist's time is in that diagnostic space. That's frustrating for clinicians to constantly be in a funding application process for clients.

Perspective: Allied health and nursing professional; regional health

6 6 I don't think that NDIS has been a great success for people with psychosocial disabilities. It has worked well for some. It has also taken away from the community-based programs—those programs that were always there to be relied on and that helped people to be part of a community.

Perspective: Lived experience representative and peer worker; PHN

An example is a case where a youth has an acquired brain injury. He's also being diagnosed with anxiety and depression, and has suicidal ideations. This person is contacting emergency services on a daily basis, pretty much threatening self-harm and harm to others. The local mental health services have determined it's not a mental health issue. It's more of a disability. So, NDIS have him on their books, but they're only able to provide sort of minimal assistance.

There appears to be a bit of a shortfall there for people in that situation. We could use a combined mental health disability service where these people can be provided with appropriate assistance. Whether it is a mental health issue and a disability issue and/or an alcohol and drug issue, we need to look at ways that we can address those things together.

Perspective: Police and mental health

6 NDIS has lots of issues for people with psychological disabilities, but it does represent one positive step. You get the right to choose from a broader number of therapies that you know works for you.

The barrier to using different therapies, like art therapy and narrative therapy, is the lack of access to MBS rebates. MBS favours psychologists and psychiatrists. If you can't register with MBS, then the people you work with must pay the full cost and many people can't do that.

I don't want the system to limit what type of therapy or which health professional I can see. I don't agree that one type of degree is more valuable than another if the therapist doesn't know anything about how to treat me. Talking therapies don't work for everyone. There are other ways that are essential, especially for people who struggle to put their experience into words. I think we are going backwards in our over-reliance on psychologists and psychiatrists. It's not a competition. With the waiting lists we have now, we need to draw on a wider professional team.

Making progress

To make progress in mental health reform, people saw the need for a system that was able to carry forward the best of what had been learned in the past, and combine this with the current insights of living experience. A commitment to longer-term funding is needed to provide the time to learn and to consolidate the approaches that work.

We have known about needs for a long time, yet lots of parts of the community are only just waking up to recognising those needs. Consumers and carers have been doing the work, advocating for reform, for a long time. A lot has gone on in the field that hasn't been acknowledged. So many people have put in effort to get us to this point. There is little understanding of the work that has been done over the years.

There are lots of great resources out there that seem to get forgotten about. Resources from the 1990s, like the kit [The kit: a guide to the advocacy we choose to do, a product of the Community Development Project that aimed to enhance community sector advocacy], are still useful today if people know about them.

Sometimes, things get lost when funding runs out. Projects close, and the resources are left on the shelf. Some things, like the YES survey are used in one area, but not taken out to scale across other regions. Who is looking at these resources and helping people to connect with them? We need to stop reinventing things with every newly funded project, and start to build on what we have.

Perspective: Consumer representative and peer worker

6 6 We have developed so many resources over the years, great resources that just sit with one organisation or get put away after a project has finished. We don't build on these; we keep starting from scratch with each new project. Funding that runs out after 2 years adds to this. What happens to these resources when the funding is gone? We start again! In the meantime, we keep waiting.

Perspective: Living experience, carer and suicide prevention consultant

C The hope with pilots is that funds will be found to keep things going. We could get better continuity if we evaluated properly and made a strong business case. There is also just a common-sense argument to be made. Data can mislead. We don't collect enough information or the right information. We need to get much more detail about what is working for people in different contexts. How do we link what we have done with what lies ahead of us? Linking people and resources together. It's about networking. This is a low-cost approach that makes good common sense.

Perspective: Lived experience representative and peer worker; PHN

We need to find our positive stories. Complex problems will always be dealt with imperfectly because we are human. People will go on needing different things at different times. What we can do is strive for improvement. There has to be a core commitment for every service agency to learn and to share. There is always hope. We contribute to social change by sharing what we have learned with the wider sector.

Perspective: Consumer and lived experience worker

Moving forward

looking to the next 10 years

It is impossible to know 'are we there yet' unless we know where we want to get to, and whether we offer quality services that work. This must be from the perspective of the person and family, not just the clinician.² The purpose of reflection is to learn from our past and present experience to inform what happens next. The participants in this project have explored and shared their experiences of mental health care in Australia, identifying what is working, what is improving, and what is still needed (see <u>Summary of findings: different</u> <u>stories, shared insights</u>).

These insights address the touchpoints where the structure of the mental health and suicide prevention system connects with services users and their families, supporters, communities, and service providers. This is a different approach to the more traditional measurement of the number of services delivered or clinical outcomes.

Gadhungal Murring

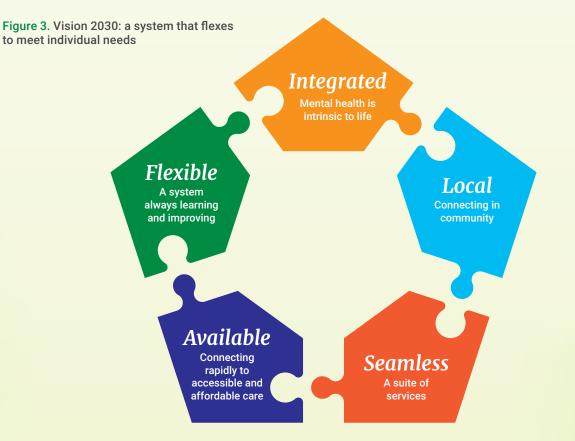
Substantial mental health inquiries and reform activities have been undertaken over the past few years. These have all pointed in the same direction towards a more personcentred and flexible approach to mental health care.

However, a shared understanding of the difficulties has not been matched by a shared view of what success looks like. The Commission's <u>Vision 2030</u>, launched in 2022, grew from a broad consultation with stakeholders to articulate a shared view of a well-functioning mental health system.

The perspective articulated by the Commission's Vision 2030 roadmap is similar to that of the people who shared their reflections in this project. This perspective looks like a system of care that responds to a person and their family and supporters, and that responds flexibly to changes in needs, regardless of the person's geographic location, age, economic circumstances, diagnosis or cultural group. This is a system that responds to diversity, and accommodates the complexity of individual experience.

To achieve these goals, a diverse range of services and agencies must be connected. We will continue to need high-quality clinical care, but an effective integrated system will also incorporate local grassroots community initiatives and social supports, education, veterans' services and employment. It is a collaborative rather than hierarchical approach. Instead of trying to identify solutions and mandating the implementation of services that will fit everyone, the system supports the development of diverse local solutions that are right for their context.

The 5 domains of activity in Vision 2030 (Figure 3) are not a list of check points, but a framework to understand the experiences of people whose lives are affected by the mental health system. Continuing to measure individual experience, and to ask about the experience of change, and not just about problems and barriers to change, will remain an important part of the Commission's ongoing role as it reports on the progress of mental health reform.



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